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Feedback of Patient Reported Outcomes to healthcare professionals for comparing health service performance: A scoping review

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Feedback of Patient Reported Outcomes to healthcare professionals for comparing health service performance: A scoping review.

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Author Contribution

All authors were involved in the planning of the project. Shaun Hancock, Olivia Ryan, and Violet Marion were involved in the search strategy, extraction and synthesis of data, and wrote the manuscript in consultation with Sharon Kramer, Sibilah Breen, and Dominique Cadilhac. All authors contributed to the final version of the manuscript.

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Competing interests

The authors declare that they have no competing interests.

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Feedback of Patient Reported Outcomes to healthcare professionals for comparing health service performance: A scoping review.

Abstract

Objective: Patient reported outcomes (PROs) provide self-reported patient assessments of their quality of life, daily functioning, and symptom severity after experiencing an illness and having contact with the health system. Feeding back summarised PRO data, aggregated at the health-service level, to healthcare professionals may inform clinical practice and quality improvement efforts. However, little is known about the best methods for providing these summarised data in a way that is meaningful for this audience. Therefore, this scoping review aims to summarise the emerging approaches to PROs ‘service-level’ feedback to healthcare professionals.

Setting: Healthcare professionals receiving patient reported outcome data feedback at the health-service level.

Data sources: Databases selected for the search were Embase, Ovid Medline, Scopus, Web of Science, and targeted web-searching. The main search terms included: ‘patient-reported outcome measures’, ‘patient-reported outcomes’, ‘patient-centred care’, ‘value-based care’, ‘quality improvement’ and ‘feedback’. Studies included were those that were published in English between January 2009 and June 2019.

Primary and secondary outcome measures: Data were extracted on the feedback methods of PROs to patients or healthcare providers. A standardised template was used to extract information from included documents and academic publications. Risk of bias was assessed using Joanna Briggs Institute Levels of Evidence for Effectiveness.

Results: Overall, 3479 articles were identified after de-duplication. Of these, 18 academic publications and 21 documents from the grey literature were included in the final review. Guiding principles for data display methods and graphical formats were identified. Seven

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major factors that may influence PRO data interpretation and use by healthcare professionals were also identified.

Conclusion: While a single best format or approach to feedback PRO data to healthcare professionals was not identified, numerous guiding principles emerged to inform the field.

Strengths and limitations of this study

- This scoping review provides a novel summation of the published and grey literature of the guiding principles for effectively feeding back Patient Reported Outcome data to healthcare providers.
- The search strategy used was broad, including individual patient level, health-service level, and system level reporting of Patient Reported Outcome data to ensure no relevant articles were missed.
- The synthesis of the literature was focussed primarily on health-service level reporting of aggregate Patient Reported Outcome data to healthcare professionals to inform the rapidly growing field of improvement science and implementation research.

INTRODUCTION

There is growing interest in the use of Patient Reported Outcomes (PROs) for all aspects of health care. This is because information available from administrative and routinely collected clinical data do not provide a comprehensive picture related to health outcomes once patients leave hospital.¹ PROs are outcome data collected directly from patients about their health and the potential impacts of treatments or management within the health system.² PROs are differentiated from Patient Reported Outcome Measures (PROMs), which are the instruments or survey tools used to obtain PROs.³ Reporting of PRO data can occur at the individual patient level and be used to inform decisions about patient-centred care, or at the aggregated service and system levels, and may be used to assess and compare organisational performance or for population ‘burden of disease’ surveillance.^{4 5}

PROs were originally developed for use in research, such as comparative studies and clinical trials.^{6 7} However, the value of using PROs to inform clinical practice has since been realised.^{8 9} PROs have evolved in a somewhat disparate manner between different countries, with each country aligning the use of PRO collections with a slightly different emphasis.⁵ For example, in England the focus of PRO collections is on hospital performance in selected elective surgeries, whereas in the Netherlands and Sweden, collection of PROs predominately occurs through disease-specific Clinical Quality Registries (CQRs).⁵

Healthcare professionals have reported challenges in relation to interpreting the meaning and implications of PRO data.^{6 10} These challenges can arise due to the variation by which PROs are used, scored, and how the resultant PRO data are reported.⁶ Methods for optimising the feedback of PRO data to healthcare professionals is an emerging field of research.^{2 11 12} Currently, little is known about the best methods for providing summarised PRO data in a way that is meaningful for health care providers. To the best of our knowledge,

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there are no scoping reviews that have been published in which the evidence of PRO feedback methods to this audience has been synthesised.

The aim of this review was to investigate the emerging approaches to PRO feedback and reporting to healthcare professionals. Three questions were explored: (1) What is the existing evidence on best practice in the readability and feedback of PRO data to healthcare professionals? (2) What PRO data presentation formats have the most utility for healthcare professionals? (3) Are there environmental/structural/behavioural factors that influence PRO data interpretation or use?

METHODS

The methods used for the review (including inclusion criteria, search strategy, extraction and synthesis) were specified in advance in an unpublished protocol. Two search strategies were used. The first covered the academic, peer reviewed literature and the second covered grey literature (such as government reports and policy documents). Different strategies were used to search the two sources of evidence. Systematic and rapid review methods using recommended approaches by the Cochrane collaboration¹³ were drawn upon for this scoping review. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) was used for report results.¹⁴

Academic Literature Search

For the academic literature, four databases were selected to search, including: Embase; Ovid Medline; Scopus; and Web of Science. These databases were chosen to maximise the scope of articles that were retrieved. The search included term related to the following terms and concepts: patient-reported outcome measures, patient-reported outcomes, patient centred care, value-based care, quality improvement, feedback, audit, and dashboard. A full list of search terms and the combinations used is available in Supplemental Table 1.

Studies included were those that were published in English between January 2009 and June 2019, where the feedback methods of PROs to patients or healthcare providers were described. Studies prior to 2009 were excluded to accommodate a contemporary, timely and comprehensive summary. Abstract booklets, conference abstracts, and newsletters, were excluded. Publications for studies that were pilot/development/protocol projects, focused on testing a PRO tool, or in which PROs were used as the endpoint outcome for an observational or comparative-effectiveness study were excluded. Further, studies related to primary care, emergency care or non-acute conditions (e.g. surgical interventions or interventional devices) were also excluded. The initial search was broad to include studies related to individual patient-level feedback of PRO data to ensure no relevant articles were missed, however, the synthesis of the literature focussed primarily on health-service level reporting of aggregate PRO data to healthcare professionals.

All references identified from these searches were downloaded and imported into Covidence software.¹⁵ Following removal of duplicates, the screening process involved one reviewer reading the titles and abstracts of each article to determine relevance. The full text of the relevant articles was then assessed by one reviewer (SH), with a second reviewer (CW) conducting an independent assessment on a subset of the articles to ensure standardisation. If any disagreements for study eligibility arose, these were resolved through discussion and consensus between the two reviewers. If disagreements were unable to be resolved using this approach, the article was to be reviewed by a third reviewer to determine eligibility. This latter process was not required.

Data from the included articles were systematically extracted using a predetermined data extraction template by one reviewer (SH). The extraction template was piloted by the review team and adapted as necessary. The final extraction template included: characteristics of study participants (including age, profession, area of practice, and number of participants),

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type of article, which PROs were used, the purpose of the feedback, and the outcomes of the study.

Level of Evidence and Critical Appraisal of the Academic Literature

The methodological design of all included articles were assessed according to the Joanna Briggs Institute Levels of Evidence for Effectiveness.¹⁶ Studies were assigned Level 1 (experimental), Level 2 (quasi-experimental), Level 3 (analytical), Level 4 (descriptive) or Level 5 (expert opinion). Further, the included research articles were appraised for strength of evidence by one reviewer (SH) using the critical appraisal tools from the Joanna Briggs Institute.¹⁷ Each article was assigned a rating of quality based on how many of the criteria the article fulfilled (e.g. “Were the criteria for inclusion in the sample clearly defined?”). Studies that met all criteria were rated as very high, studies that met 80% or more of criteria were rated as high, studies that met 60% or more, 40% or more, and less than 40% of the criteria were rated as moderate, low, and very low respectively.

Grey Literature

We elected to use similar methods to those of a previous PRO literature search conducted by Williams and colleagues (2016).⁵ The grey literature component of our search included Google searches, targeted website searches and snowballing of reference lists, where appropriate. The first ten results retrieved from each Google search were reviewed.⁵ The following search terms were used:

- ‘Use of Patient-Reported Health Outcome Measures in (country)’
- ‘Feedback of Patient-Reported Health Outcome Measures in (country)’
- ‘patient-reported outcome measure + feedback + use in (country)’
- ‘Benchmarking of Patient-Reported Health Outcome Measures in (country)’

The countries included in the Google searches were Sweden, The Netherlands, Finland, Canada, United Kingdom, United States of America (USA) and Australia. The websites of relevant leading organisations (i.e. health agencies, government organisations, professional organisations, special interest groups, research institutes and universities) were also searched. For example, the websites of organisations such as: The Institute for Healthcare Improvement (IHI), The International Consortium for Health Outcomes Measurement (ICHOM) (i.e. the United States), The Dutch Institute for Clinical Auditing (DICA) (i.e. The Netherlands) and The Organisation for Economic Co-operation and Development (OECD) were searched. Further, the websites and Annual Reports of national clinical quality registries that were known to collect and report PRO data were also searched. Data from included documents were systematically extracted using a predetermined data extraction template by two reviewers (OR and VM).

The findings from the academic and grey literature templates were synthesised by consensus into addressing each of the separate research questions. The preferences of PRO data formats among healthcare professionals determined in the current study was summated from all articles that described PRO data formats preferences.

Patient and Public Involvement

No patient involved.

RESULTS

The initial search resulted in the identification of 4445 academic articles. Following the removal of duplicates 3479 unique articles remained, eighteen of which were included in the final review. **Error! Reference source not found.** summarises the academic literature search using a PRISMA flowchart.¹⁸ The publication characteristics, level of evidence and quality appraisal of the included academic literature are available in Table 1. Research methods included two reviews,^{19 20} three case studies,^{12 21 22} two consensus panels^{11 23} and 11

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observational studies.^{2 6 24-32} According to the Joanna Briggs Institute Levels of Evidence for Effectiveness,¹⁶ the 18 included studies were classified according to the following levels: 1 (n=0), 2 (n=1), 3 (n=3), 4 (n=12), 5 (n=2). The studies were primarily conducted in United States of America, Australia, Canada, and European countries. From the grey literature search, 103 materials were determined to be topically relevant and were scanned for further information. Of these, a total of 21 were included in the final review.

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<insert Table 1 here>

The following results are presented by research question.

1. What is best practice in the readability and feedback of PRO data to healthcare professionals?

Overall, the current evidence base provides some general guidance but inadequately describes specific optimal data display methods for the feedback of PRO data to healthcare professionals. From this review, several issues related to the reporting of PRO data to health professionals were explored and summarised, and recommendations identified to address these issues are provided below.

A number of authors suggested that in order to engage health professionals in reviewing PRO data, PRO reports need to be simplistic and easy to read.^{19 20} Suggested modifications to improve readability of feedback interventions included: reducing the number of metrics (i.e. outcomes) presented within a report, minimising page counts, avoiding 3-dimensional graphical elements, uncluttering reports to increase readability and including instructions where they will be needed.³³

Six publications addressed the issue of directionality of PRO scores in graphical displays.^{2 11 12 29 32 34} A consensus panel found that there was no intuitive interpretation of

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3 symptom scores, with some people expecting higher scores to mean ‘better’ and other people
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5 expecting higher scores to mean ‘more’ of the symptom (and therefore worse).¹¹ Healthcare
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7 professionals interpretation accuracy has been demonstrated to be greater for line graphs
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9 when higher scores indicated ‘better’ rather than indicating ‘more’.³⁴ Despite these results,
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11 cation should be taken when modifying the directionality of PROs in order for all symptom
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13 scores to have the same directionality, due to potential confusion associated with
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15 inconsistencies across instruments.¹¹ One suggestion to avoid potential confusion is to
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17 provide a label to denote ‘better’ alongside the chart to indicate the directionality of the
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19 PRO,^{2 32} or use coloured arrows; green for better scores, and red arrows for worse scores.²⁹
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21 Further, the provision of a written explanation of the PRO score alongside the graph, has also
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23 been recommended to assist with interpretation.³³ Written explanations are particularly
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25 valuable for complex graphical displays.^{25 31} Another suggestion is to include descriptive
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27 labels (e.g. mild/moderate/severe) alongside the chart, assuming data to support the use of
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29 these thresholds are available.^{11 22} The use of ‘traffic-light’ colours to colour-code the
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31 thresholds has also been recommended to allow a quick and easy review.^{24 28-30}
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38 Displaying a reference population to use as a comparison can also be considered for
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40 inclusion, provided these data are available.¹¹ Reference populations, such as national
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42 averages or relevant norm information for peer groups, can help provide context for the
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44 interpretation of the PRO scores.³¹ However, there is a need to balance the complexity of
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46 presenting additional data and the healthcare professionals’ ability to understand the data.¹¹
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48 Furthermore in an exploratory study participants warned that providing comparison data can
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50 have unintended consequences, such as negative comparisons leading to reputational damage
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52 when the health service or healthcare professional is reported to be lesser performing in their
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54 PROs results.³¹
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A cross-sectional mixed methods study in oncology reported that healthcare professionals indicated a preference towards the inclusion of statistical details for PRO data.⁶ There is a move away from reporting the p-value alone to illustrate statistical significance, and instead the use confidence intervals is encouraged.^{6 11} The clinically important difference should also be included within the graphical representation of the PRO results, where appropriate.^{11 20} Though an asterisk is not recommended to indicate clinically important differences, as that symbol is commonly used to indicate statistical significance.¹¹ Patients can find the inclusion of clinically important differences confusing,⁶ but it is valuable for them to know if the difference matters.¹¹

2. What PRO data presentation formats have the most utility for healthcare professionals?

There are many different formatting approaches that have been used to display PRO results. Table 2 provides a summary of different formats that have been utilised to display PRO data, as well as an indication of the preference among healthcare professionals. Line graphs and bar graphs were identified as the most familiar and preferred format amongst healthcare professionals for comparing and reviewing their service.

<insert Table 2 here>

3. Are there environmental/structural/behavioural factors that influence PRO data interpretation or use?

Within the current body of literature several barriers and enablers associated with the use and uptake of PROs among healthcare professionals have been identified. However, the evidence base addressing these proposed challenges, or explicit recommendations to enable successful adoption of PROs among healthcare professionals, is limited.^{1 35} We identified seven factors that influence the interpretation of PROs: missing data, government and local leadership, healthcare professional education and training, engaging healthcare professionals

to overcome resistance to change in clinical practice, casemix adjustment, interoperability of information and communication technology (ICT) systems, and frequency/timeliness of feedback.

Missing data.

Missing data poses a challenge with analysis and reporting of PRO results. Missing PRO data may be unavoidable due to a multitude of reasons. There may be specific population groups with missing PRO responses, or sensitive and difficult questions that may be omitted.³⁶ Consequently, these instances may result in scepticism about completeness of the data among healthcare professionals.³⁷

Achievement of high participation and completion rates at follow-up, both individually and at the aggregate level influences overall usefulness of PRO data.³⁸ However, due to the complex nature of PROs and their inevitable incompleteness in certain cases, strong evidence through a statistical analysis plan may assist in ensuring the resulting analyses and reports are unaffected by missing data.³⁶

The role of government and local leadership.

It has been reported that ‘top-down’ approaches to PRO implementation whereby government or management is driving the implementation process and performing the assessment and taking actions based on the rules, may be met with resistance from healthcare professionals.⁴ These endeavours can be complemented with ‘bottom-up’ approaches where PRO implementation is clinically driven and is more focused on quality improvement.⁴ The use of the data from these collection approaches can be reported back at the micro level (to inform decision for individual patient care), as well as the meso level (to assess performance of services and quality improvement) or the macro level (to assess healthcare systems).^{4 5} Importantly, the most evidence for effectiveness of PRO feedback exists at the meso level.⁵

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Further, clinical/local champions and stakeholder initiatives are crucial to enhance healthcare professionals’ engagement with collecting and use of PRO data.³⁵ Specifically, clinical champions may contribute to broader dissemination and use of PRO data among clinical units or within health services (Aspex Consulting, Evaluation Framework and Initial Appraisal of PROMS: Final Report, personal communications, 2018).

Healthcare professional education and training.

Healthcare professionals may not understand PRO data or know what to do with the results.³⁸
³⁹ There is a need to increase PRO-specific training and education to aid healthcare professionals’ ability to; interpret PRO data, integrate the use of PROs into clinical practice, and respond to concerning PRO results.^{40 41} There is currently no recommendation for how to direct healthcare professionals to use and interpret PRO data or for how to respond to concerning results in a standardised, clinically appropriate manner.^{38 42} For example, our review found the need for disease management pathways to be developed as a resource to respond to issues identified through PRO results.⁴² Implementation of a PRO training course has been demonstrated to improve attitudes and self-efficacy from healthcare professionals towards PRO data within the child mental health services.²⁶

Engaging healthcare professionals to overcome resistance to change in clinical practice.

There may be a lack of buy-in among the clinical community when healthcare professionals are uncertain or lack confidence in understanding how PRO results could be used to improve their clinical practice.⁴³ As such, PROs should be implemented in a way that can be directly translated into specific actions for healthcare professionals, with clear recommendations on how to respond to PRO scores in clinical settings.^{21 23} Additional recommendations to improve healthcare professional buy-in include: co-designing data display formats and information content with healthcare professionals’ input to ensure the

formats meet their needs,^{20 38 39} and showcasing benefits to help health professionals see the merits of using PRO data.^{24 44}

Analyses that include adjustment for differences in patient characteristics (casemix adjustment).

Due to the differing characteristics of patients admitted to different health services, comparing outcomes between hospitals without casemix adjustment may be misleading.³⁵ Casemix adjustments are particularly important to healthcare professionals.³⁵ Casemix adjustment uses statistical models to account for known variables that affect health (such as age, gender, ethnicity, symptom severity, and socio-economic background) to predict what each hospital's outcomes would be for a standard patient or population.¹ The development of casemix adjustment methods for PRO data are a widely recognised challenge in the field.^{1 35 45} For example, patients may be influenced by cultural, development or personality differences, contextual factors or life circumstances; and different health experiences or events when interpreting and responding to questions related to their health.³⁵ Importantly, casemix adjustment for PROs needs to be disease/condition-specific, since demographic factors that may influence patients' responses to PROs are likely to vary across patient cohorts and clinical settings.⁴³ Published evidence related to the development of casemix adjustment methods for PRO data is limited. Further development and refinement of robust casemix adjustment methods is required to guide meaningful interpretation and use of PRO data.^{1 35 46}

Interoperability of Information and Communication Technology (ICT) systems.

A lack of efficient, interoperable health information systems and robust data governance frameworks are a significant barrier to integration and reporting of PROs.^{45 47} ICT system interoperability issues prohibit patient-level linkage between datasets, impacting

upon the ability to conduct risk-adjustments and draw meaningful conclusions from some PRO collections.⁴⁵

Frequency/timeliness of feedback.

Perceived time lags associated with PRO data feedback, such as reports fed back annually, may lead to information being discounted as irrelevant.^{33 35 48} One solution is to routinely report PRO results to healthcare professionals or provide the capacity for clinical teams to continuously retrieve and review their own data.^{37 49} Conversely, too much feedback could result in ‘alert fatigue’, which may lead healthcare professionals to ignore the PRO results.²⁴ Despite reporting delays as a known barrier to healthcare professionals uptake of PROs, optimal intervals for feedback have seldom been investigated in this area.³³ One suggested timing for audit and feedback to professional practice is 1-4 times a year for process and outcome indicators, but more frequently where there is greater possibility for improvement.³¹

A summary of the overall prevailing consensus-based guiding principles are outlined in Box 1.

<insert box 1>

DISCUSSION

PRO data may be used to improve the safety and quality of healthcare, but in order to achieve this, it is critical that feedback methods are optimised. This scoping review provides a novel summation of the published and grey literature of the guiding principles for effectively feeding back Patient Reported Outcome data to healthcare providers. The overall synthesis of the literature revealed various issues that provide opportunities to advance this field.

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7 based approaches.
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12 literature that informs graphical presentation of clinical data in general. This extensive
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14 research can inform understanding for the graphic representation of PROs. For example,
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16 similar graphical display features have been demonstrated in other forms of feedback to
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18 clinicians. In a review of quality dashboards used in clinical settings Dowding et al (2015)
19
20 found that most dashboards used the 'traffic light' colour coding in their displays to indicate
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22 what type of action is required. Converse to the suggestions made in the current review,
23
24 Dowding et al (2015) found that most dashboards used a table format to represent the data.
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26 Providing peer group data or benchmarking to enable comparison of current in clinical audit
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28 and feedback is also a common technique to improve engagement.^{50 51}
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33 Further, recommendations to improve knowledge translation have been identified in
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35 other types of clinical audit and feedback. Multiple clinical audit and feedback studies have
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37 indicated that feedback is more effective when there is a local champion.^{52 53} The timeliness
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39 and actionability of the feedback are other factors that is consistently mentioned for effective
40
41 clinical feedback.^{51 52 54 55} These findings are in line with the current study. Additional factors
42
43 to improve the effectiveness of feedback include: providing feedback both verbally and in
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45 written format, and using feedback to decrease rather than increase certain behaviours.⁵²
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49 There have also been several initiatives to develop guidance on communicating data
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51 in general, which can further inform the development of PRO data feedback. In the guide by
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53 the National Cancer Institute,⁵⁶ several suggestions for how to present data effectively are
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55 given, and multiple are in line with the current review, including: the use of labels and the use
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57 of colour. There are also additional suggestions including: the use of verbal qualifiers or
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metaphors to help explain the meaning of the numbers and rounding most decimals to the nearest whole number for easy of understanding. Simpson (2015) provides guidance for how to choose the appropriate graph type.⁵⁷ Nominal and ordinal data can be displayed using a pie graph or car chart, but interval and ratio data may have too many categories to be displayed in a pie chart. Further, box plots are best used to display variables that are not normally distributed.

Strengths of our review included that each reviewer used a pre-defined protocol and the information from the included literature was summarised using a template to ensure consistency. Despite the use of the rigorous search strategy within the current review, several limitations deserve comment. Due to the available timeframe both the academic and grey literature search and screening process were largely conducted by a single reviewer. This may have resulted in selection and interpretation bias as some relevant literature may have been overlooked. Overall, we found limited high-quality published evidence related to optimal feedback methods and formats for PRO data. Our findings here suggest that there is a need for more rigorous testing of PRO feedback methods in the future.

Future directions

PROs represent a key building block required to move towards a health system that can assess the value of healthcare from a consumer’s perspective (Paxton Partners, Patient-Reported Outcome Measures: Literature scan, personal communication, 2018). Little is known about the best way to feedback PRO data effectively to healthcare providers in considering the performance of their health services compared with peer services. We sought to summarise the current evidence base and use this information to facilitate a process to determine the best methods for future implementation of PRO reporting. As part of planned future work associated with the Australian Stroke Clinical Registry (AuSCR)^{58 59} we seek to test various formats based on our findings and extend the work conducted to date. AuSCR is

one of the few national stroke clinical registries around the world to collect PROs.⁶⁰ The outcome of this work will also inform the field and may be adopted by other Clinical Quality Registries.

Conclusion

While ‘best practice’ feedback methods and presentation formats of PRO data to healthcare professionals are emerging, there remains many unanswered questions. The basic guiding principles and recommendations presented in the body of the current review draw upon the findings of the prevailing, consensus-based literature. Further research is required to determine what healthcare professionals perceive to be simple, easy-to-read and interpretable PRO reports for aggregated data. Healthcare professionals require support to interpret the data and should be part of the process of co-designing formats that will be the most meaningful to them. Our work here provides some guidance towards these efforts.

References

1. Canadian Institute for Health Information (CIHI). Health outcomes of care: An idea whose time has come. Ottawa, Ontario., 2012:1-52.

2. Brundage M, Blackford A, Tolbert E, et al. Presenting comparative study PRO results to clinicians and researchers: Beyond the eye of the beholder. *Quality of Life Research* 2018;27(1):75-90. doi: 10.1007/s11136-017-1710-6

3. Thompson C, Sansoni J, Morris D, et al. Patient-reported Outcome Measures: An environmental scan of the Australian healthcare sector. ACSQHC: Sydney, NSW: Australian Commission on Safety and Quality in Health Care, 2016:89.

4. Desomer A, Van Den Heede K, Triemstra M, et al. Use of patient-reported outcome and experience measures in patient care and policy: Belgian Health Care Knowledge Centre, 2018:1-151.

5. Williams K, Sansoni J, Morris D, et al. Patient-reported outcome measures: Literature review. ACSQHC: Sydney, NSW: Australian Commission on Safety and Quality in Health Care, 2016:1-91.

6. Brundage MD, Smith KC, Little EA, et al. Communicating patient-reported outcome scores using graphic formats: Results from a mixed-methods evaluation. *Quality of Life Research* 2015;24(10):2457-72. doi: 10.1007/s11136-015-0974-y

7. Santana MJ, Haverman L, Absolom K, et al. Training clinicians in how to use patient-reported outcome measures in routine clinical practice. *Quality of Life Research* 2015;24(7):1707-18. doi: 10.1007/s11136-014-0903-5

8. Ahmed S, Berzon RA, Revicki DA, et al. The use of patient-reported outcomes (PRO) within comparative effectiveness research: Implications for clinical practice and health care policy. *Medical Care* 2012;50(12):1060-70. doi: 10.1097/MLR.0b013e318268aaff

- 1
2
3 9. Proding B, Taylor P. Improving quality of care through Patient-Reported Outcome
4
5 Measures (PROMs): Expert interviews using the NHS PROMs Programme and the
6
7 Swedish quality registers for knee and hip arthroplasty as examples. *BMC Health*
8
9 *Services Research* 2018;18:1-13. doi: 10.1186/s12913-018-2898-z
- 10
11
12 10. Brundage M, Bass B, Jolie R, et al. A knowledge translation challenge: Clinical use of
13
14 quality of life data from cancer clinical trials. *Quality of Life Research*
15
16 2011;20(7):979-85.
- 17
18
19 11. Snyder C, Smith K, Holzner B, et al. Making a picture worth a thousand numbers:
20
21 Recommendations for graphically displaying patient-reported outcomes data. *Quality*
22
23 *of Life Research* 2019;28(2):345-56. doi: 10.1007/s11136-018-2020-3
- 24
25
26 12. Arcia A, Woollen J, Bakken S. A systematic method for exploring data attributes in
27
28 preparation for designing tailored infographics of patient reported outcomes. *eGEMs*
29
30 2018;6(1):1-9. doi: 10.5334/egems.190
- 31
32
33 13. Cochrane Training. Online learning 2019 [Available from:
34
35 <https://training.cochrane.org/online-learning>.
- 36
37
38 14. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-
39
40 ScR): Checklist and Explanation. *Annals of Internal Medicine* 2018;169(7):467-73.
41
42 doi: 10.7326/M18-0850
- 43
44
45 15. Covidence systematic review software, [program]. Melbourne, Australia: Veritas Health
46
47 Innovation.
- 48
49
50 16. Joanna Briggs Institute. JBI Levels of Evidence 2014 [Available from:
51
52 [https://joannabriggs.org/sites/default/files/2019-05/JBI-Levels-of-](https://joannabriggs.org/sites/default/files/2019-05/JBI-Levels-of-evidence_2014_0.pdf)
53
54 [evidence_2014_0.pdf](https://joannabriggs.org/sites/default/files/2019-05/JBI-Levels-of-evidence_2014_0.pdf).
- 55
56
57 17. Joanna Briggs Institute Reviewer's Manual: The Joanna Briggs Institute 2017.
- 58
59
60

18. Moher D, Liberati A, Tetzlaff J, et al. Preferred Reporting Items for Systematic Reviews and Meta Analyses: The PRISMA Statement. *PLoS Med* 2009;6(7):e1000097. doi: doi:10.1371/journal.pmed1000097
19. Bantug ET, Coles T, Smith KC, et al. Graphical displays of patient-reported outcomes (PRO) for use in clinical practice: What makes a pro picture worth a thousand words? *Patient Education and Counseling* 2016;99(4):483-90. doi: <http://dx.doi.org/10.1016/j.pec.2015.10.027>
20. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: A systematic review of qualitative research. *BMJ Quality & Safety* 2014;23(6):508. doi: 10.1136/bmjqs-2013-002524
21. Forsberg HH, Nelson EC, Reid R, et al. Using patient-reported outcomes in routine practice: Three novel use cases and implications. *Journal of Ambulatory Care Management* 2015;38(2):188-95. doi: 10.1097/JAC.0000000000000052
22. Oliver BJ, Nelson EC, Kerrigan CL. Turning feed-forward and feedback processes on patient-reported data into intelligent action and informed decision-making: Case studies and principles. *Medical Care* 2019;57 (Supplement 1):S31-S37. doi: <https://dx.doi.org/10.1097/MLR.0000000000001088>
23. Jensen RE, Snyder CF, Basch E, et al. All together now: Findings from a PCORI workshop to align patient-reported outcomes in the electronic health record. *Journal of Comparative Effectiveness Research* 2016;5(6):561-67. doi: 10.2217/ce-2016-0026
24. Aiyegbusi OL, Kyte D, Cockwell P, et al. Patient and clinician perspectives on electronic patient-reported outcome measures in the management of advanced CKD: A

- qualitative study. *American Journal of Kidney Diseases* 2019;74(2):167-78. doi: 10.1053/j.ajkd.2019.02.011
25. Allwood D, Hildon Z, Black N. Clinicians' views of formats of performance comparisons. *Journal of Evaluation in Clinical Practice* 2013;19(1):86-93. doi: 10.1111/j.1365-2753.2011.01777.x
26. Edbrooke-Childs J, Wolpert M, Deighton J. Using Patient Reported Outcome Measures to Improve Service Effectiveness (UPROMISE): Training clinicians to use outcome measures in child mental health. *Administration and Policy in Mental Health and Mental Health Services Research* 2016;43(3):302-08. doi: 10.1007/s10488-014-0600-2
27. Hartzler AL, Izard JP, Dalkin BL, et al. Design and feasibility of integrating personalized PRO dashboards into prostate cancer care. *Journal of the American Medical Informatics Association* 2016;23(1):38-47. doi: 10.1093/jamia/ocv101
28. Hildon Z, Allwood D, Black N. Making data more meaningful: Patients' views of the format and content of quality indicators comparing health care providers. *Patient Education and Counseling* 2012;88(2):298-304. doi: 10.1016/j.pec.2012.02.006
29. Kuijpers W, Giesinger JM, Zubernigg A, et al. Patients' and health professionals' understanding of and preferences for graphical presentation styles for individual-level EORTC QLQ-C30 scores. *Quality of Life Research* 2016;25(3):595-604. doi: 10.1007/s11136-015-1107-3
30. Talib TL, DeChant P, Kean J, et al. A qualitative study of patients' perceptions of the utility of patient-reported outcome measures of symptoms in primary care clinics. *Quality of Life Research* 2018;27(12):3157-66. doi: 10.1007/s11136-018-1968-3

31. van Overveld LFJ, Takes RP, Vijn TW, et al. Feedback preferences of patients, professionals and health insurers in integrated head and neck cancer care. *Health Expectations* 2017;20(6):1275-88. doi: 10.1111/hex.12567
32. Wu AW, White SM, Blackford AL, et al. Improving an electronic system for measuring PROs in routine oncology practice. *Journal of cancer survivorship : research and practice* 2016;10(3):573-82. doi: <http://dx.doi.org/10.1007/s11764-015-0503-6>
33. Brehaut J, Colquhoun H, Eva K, et al. Practice Feedback Interventions: 15 Suggestions for Optimizing Effectiveness. *Annals of Internal Medicine* 2016;164(6):435-41. doi: 10.7326/M15-2248
34. Snyder C, Brundage M, Smith KC, et al. Testing Ways to Display Patient-Reported Outcomes Data for Patients and Clinicians. Washington, DC: Patient-Centered Outcomes Research Institute (PCORI), 2018:1-163.
35. Canadian Institute for Health Information (CIHI). CIHI PROMs Forum Proceedings. Ottawa, Ontario, 2015:41.
36. Cappelleri J, Zou K, Bushmakina A, et al. Patient-Reported Outcomes: Measurement, Implementation and Interpretation. Boca Raton, FL: CRC Press 2014.
37. Peterson A. Learning and understanding for quality improvement under different conditions - An analysis of quality registry-based collaboratives in acute and chronic care. Jönköping University, 2015.
38. Nelson E, Hvitfeldt H, Reid R, et al. Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case studies from Dartmouth, Karolinska and Group Health. Lebanon, New Hampshire: The Dartmouth Institute for Health Policy and Clinical Practice, 2012:1-55.
39. Duckett S, Jorm C, Danks L. Strengthening Safety Statistics: How to make hospital safety data more useful: The Grattan Institute, 2017.

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53
54
55
56
57
58
59
60
40. Clinical Oncology Society of Australia (COSA). Implementing monitoring of patient-reported outcomes into cancer care in Australia - A COSA Think Tank Report, 2018.
41. Raine R, Fitzpatrick R, Barratt H, et al. Patient-reported outcome measures and the evaluation of services. Challenges, solutions and future directions in the evaluation of service innovations in health care and public health: National Institute for Health Research 2016.
42. Aaronson N, Elliott T, Greenhalgh J, et al. User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice. Version 2: January 2015: International Society for Quality of Life Research 2015:1-47.
43. Chen J. Integrated Care: Patient reported outcome measures and patient reported experience measures - A rapid scoping review. Sydney: NSW Agency for Clinical Innovation, 2015:1-116.
44. Canadian Institute for Health Information (CIHI). PROMs Background Document. Ottawa, Ontario, 2015:1-38.
45. World Economic Forum. Value in healthcare laying the foundation for health system transformation. Cologny/Geneva, Switzerland: World Economic Forum, 2017:1-40.
46. Franklin P, Chenok K, Lavalee D, et al. Framework to guide the collection and use of Patient-Reported Outcome Measures in the learning healthcare system. *Generating Evidence & Methods to improve patient outcomes* 2017;5(1):17. doi: 10.5334/egems.227
47. Batalden P, Corrigan, J, Harrison, W, Kerrigan, C and Øvretveit, J. Enabling uptake of a registry-supported care and learning system in the United States: A report to the Robert Wood Johnson Foundation from Karolinska Institutet and The Dartmouth Institute, 2014.

48. Canadian Institute for Health Information (CIHI). Patient-centred measurement and reporting in Canada launching the discussion toward a future state. Ottawa, Ont., 2017:1-46.
49. NSW Agency for Clinical Innovation. Patient Reported Measures – Program overview. Chatswood: ACI, NSW, 2018:18.
50. Ray-Barruel G, Ullman AJ, Rickard CM, et al. Clinical audits to improve critical care: Part 2: Analyse, benchmark and feedback. *Australian Critical Care* 2018;31(2):106-09. doi: <https://doi.org/10.1016/j.aucc.2017.04.002>
51. Colquhoun H, Michie S, Sales A, et al. Reporting and design elements of audit and feedback interventions: a secondary review. *BMJ Quality & Safety* 2017;26(1):54. doi: 10.1136/bmjqs-2015-005004
52. Ivers N, Jamtvedt G, Flottorp S, et al. Audit and feedback: Effects on professional practice and healthcare outcomes. *Cochrane Database of Systematic Reviews* 2012(6) doi: 10.1002/14651858.CD000259.pub3
53. Christina V, Baldwin K, Biron A, et al. Factors influencing the effectiveness of audit and feedback: nurses' perceptions. *Journal of Nursing Management* 2016;24(8):1080-87. doi: 10.1111/jonm.12409
54. Payne VL, Hysong SJ. Model depicting aspects of audit and feedback that impact physicians' acceptance of clinical performance feedback. *BMC Health Services Research* 2016;16(1):260-72. doi: 10.1186/s12913-016-1486-3
55. Hysong SJ, Best RG, Pugh JA. Audit and feedback and clinical practice guideline adherence: Making feedback actionable. *Implementation Science* 2006;1(1):9. doi: 10.1186/1748-5908-1-9
56. National Cancer Institute. Making data talk: A workbook. In: Services USDoHaH, ed. USA: National Institute of Health 2011.

- 1
2
3 57. Simpson SH. Creating a data analysis plan: What to consider when choosing statistics for
4 a study. *Can J Hosp Pharm* 2015;68(4):311-17. doi: 10.4212/cjhp.v68i4.1471
5
6
7
8 58. Cadilhac DA, Lannin NA, Anderson CS, et al. Protocol and pilot data for establishing the
9 Australian Stroke Clinical Registry. *International Journal of Stroke* 2010;5(3):217-26.
10 doi: 10.1111/j.1747-4949.2010.00430.x
11
12
13
14 59. Cadilhac Dominique A, Andrew Nadine E, Lannin Natasha A, et al. Quality of acute care
15 and long-term quality of life and survival. *Stroke* 2017;48(4):1026-32. doi:
16 10.1161/STROKEAHA.116.015714
17
18
19
20
21 60. Cadilhac DA, Kim J, Lannin NA, et al. National stroke registries for monitoring and
22 improving the quality of hospital care: A systematic review. *International Journal of*
23 *Stroke* 2015;11(1):28-40. doi: 10.1177/1747493015607523
24
25
26
27
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1 **Table 1.** Characteristics of the included studies

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Aiyegbusi et al, ²⁴ 2019, UK	Semi-structured interviews and focus groups	Chronic kidney disease	12 patients with chronic kidney disease, and 22 healthcare professionals (nurses, psychologist, nephrologist, registrars and surgeons)	Thematic analysis of participants views on the use of a PROM system	Healthcare professionals suggested graphical representations of PROM feedback (rather than numeric), and to include “traffic light” colour-coding for quick and easy review. Healthcare professionals believed that “alert fatigue” from PROM feedback could be a barrier to use of PROM data, with the numerous alerts being provided to healthcare professionals encouraging them to ignore the PROM results.	Q1 Q3	Level 4	Moderate
Allwood et al, ²⁵ 2013, UK	Structured focus groups	All healthcare areas	107 healthcare professionals (including consultants, junior doctors, nurses and allied health professionals)	Thematic analysis of participants comprehension and format preference for PROM data.	Healthcare professionals were generally positive about the use of bar charts and caterpillar plots for the display of PROM results. Opinions were mixed for the use of tables, funnel plots, and spider plots. Healthcare professionals found that tables with icons were insufficient.	Q1 Q2	Level 4	High
Arcia et al, ¹² 2018, USA	Case study	Unspecified	2 case studies of PRO feedback projects	Explore methods affecting the design decisions of PRO feedback projects	Summarises considerations that must be understood for the visualisation of PRO data, including the range and direction of scoring.	Q1	Level 4	Very low
Bantung et al, ¹⁹ 2016	Integrated literature review, dates: 1999-2014	Oncology	9 included studies	Exploring the interpretation of graphic presentations of PRO data in clinical practice	HRQOL PROs can be accurately interpreted by healthcare professionals and patients. Line graphs and bar charts were the most preferred format for PROs; patients prefer simple graphs, while healthcare professionals prefer simple graphs with confidence intervals	Q1 Q2	Level 4	High

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Boyce et al, ²⁰ 2014	Systematic review, dates: Up to 2012	All healthcare areas	16 included studies	Summarise qualitative studies that explore the experience of healthcare professionals using PROMs	Healthcare professionals value PROMs if they can be used to aid decision making. They appreciate graphical presentation that clearly depict clinically important changes. However, they can question whether the PROM data produced is an accurate reflection of care. Attitude towards the use of PROMs may be improved by engaging the healthcare professionals in the planning stage of PROMs introduction.	Q1 Q3	Level 4	High
Brundage et al, ⁶ 2015, USA	Survey followed by a semi-structured interview	Cancer	50 patients with cancer, and 20 oncology healthcare professionals (doctors and nurses)	Explore interpretation accuracy, ratings of ease-of understanding and usefulness of graphical formats. The interview explored helpful and confusing format attributes.	Both patients and healthcare professionals prefer line graphs across group-level data and individual-level data formats (compared with bar charts and cumulative distributions), but healthcare professionals prefer greater detail (i.e. statistical details) for group-level data.	Q1 Q2	Level 3	Moderate
Brundage et al, ² 2018, USA	Survey followed by an interview with healthcare professionals	Cancer	233 healthcare professionals and 248 PRO researchers	Explore interpretation accuracy and clarity ratings of graphical formats and difference score representations.	Participants were accurate in their interpretation of PRO line graphs when the directionality of the score was indicated with a label "better". Participants were more accurate in their interpretation of pie charts compared with bar graphs, for the display of proportions.	Q1 Q2	Level 3	Very High

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Edbrooke-Childs et al, ²⁶ 2016, UK	Pre-post observational study	Child mental Health	48 healthcare professionals attended the 1-day training course, 17 healthcare professionals attended the 3-day training course	Evaluate the effect of the training courses on attitudes and self-efficacy towards PROMs and feedback.	Increased time and duration of PROMS training showed greater improvement in attitudes towards PROMS, feedback attitudes and PROM self-efficacy.	Q1 Q3	Level 3	Moderate
Forsberg et al, 2015, ²¹ USA & Sweden	Case study	Pain and spin conditions, rheumatology, and private healthcare	3 case studies of PRO feedback used in routine practice	Describe the principles and lessons learned from using PROs in the 3 case studies.	Healthcare professionals need to be able to place the PRO results within the context of the patient's current clinical state, prognosis, and attitudes (e.g. a patient's health status may be declining despite receiving best care). Healthcare professionals need to know what to do with the results, such as when the results are suggesting a significant health problem.	Q3	Level 4	High
Hartzler et al, ²⁷ 2016, USA	Preliminary focus groups and interviews, followed by a pre-post study	Prostate cancer	The focus group included 60 prostate cancer survivors. 50 patients and 50 providers completed the interviews. 12 patients completed the pre-post observation	The focus groups assessed the needs of patients in relation to PROM feedback. The interviews evaluated preferred feedback methods. The pre-post study evaluated self-efficacy, satisfaction, communication, and compliance with the PRO dashboard.	Patients prioritized needs for dashboards to compare longitudinal trends and provide comparative groups. Patients and providers preferred bar charts and line graphs compared with tables and pictographs.	Q1 Q2	Level 2	Low

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Hildon et al, ²⁸ 2012, UK	Focus groups	Knee surgery	45 patients who were planning or had undergone knee surgery	Thematic analysis of patients preferred PROM format.	Patients were generally positive about the use of bar charts and caterpillar plots. Opinions were mixed for tables and tables with icons. Patients did not like funnel plots. Patients liked the use of 'traffic-light' colours scheme and did not like the use of confidence intervals.	Q1 Q2	Level 4	High
Jensen et al, ²³ 2016, USA	Workshop proceedings	All healthcare areas	519 participants (including patients, healthcare professionals, researchers, healthcare system leaders and policy makers) attended the workshop, either in-person or online	Summary of workshop outcomes	Healthcare professionals should be provided with guidance in interpreting PRO scores, as they may not know the meaning of just raw scores. Translate PROs into specific actions for healthcare professionals by establishing clear recommendations on how to respond to PRO scores in clinical settings.	Q3	Level 5	High
Kuijpers et al, ²⁹ 2016, UK, Netherlands, Austria & Poland	Questionnaire	Cancer	548 patients with cancer and 227 healthcare professionals (doctors and nurses)	Understanding of PROM scores and preferences for different formats	Patients had no preference between non-colours bar charts and non-coloured line graphs. Patients preferred coloured bar charts over coloured line graphs. Healthcare professionals showed a preference for line graphs with 'traffic-light' coloured thresholds. Understanding did not differ between graphical formats for patients or healthcare professionals.	Q1 Q2	Level 4	High

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Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Oliver et al, ²² 2019, Australia, USA & Sweden	Case study	Multiple sclerosis, spinal care, and rheumatology	3 case studies of PRO feedback used in routine practice	Features that aid in the interpretation of PROs in the 3 case studies	The use of colour coding and threshold indicators, linked decision support functions (such as predictive calculators) can aid interpretation of PRO scores.	Q1	Level 4	Very low
Snyder et al, ¹¹ 2019, USA	Consensus panel	Cancer	Participants included healthcare professionals, PRO researchers, patients and caregivers. 28 participants in meeting 1, and 27 participants in meeting 2 (participants were not mutually exclusive)	A modified Delphi process to develop recommendations for PRO data display.	Recommendations for the display of PRO data include using labelling and thresholds, not mixing score direction in a single display, accommodating both normed and non-normed scoring, displaying confidence intervals, indicating possibly concerning results.	Q1 Q2	Level 5	High
Tabil et al, ³⁰ 2018, USA	Interview	Primary care	23 patients in primary care	Thematic analysis of the patient's perception of the utility of PRO in primary care.	The patients found the colour coding severe symptoms useful but recommended the addition of 'traffic-light' colour scheme	Q1	Level 4	High

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
van Overveld et al, ³¹ 2017, Netherlands	Semi-structured interview	Head and Neck	37 patients, healthcare professionals (doctors, nurses, speech pathologist, dietician, allied health), and health insurers.	Content analysis of participants preferred PRO feedback method.	Patients want PRO feedback to include explanations of how to read the PRO graph, the inclusion of a comparison, and the feedback delivered around once a year. Healthcare professionals want PRO feedback to be simple and include a comparison groups (such as national average, best and worst performer). Healthcare professionals want PRO feedback between 1-4 times a year and receive the feedback via email.	Q1 Q2 Q3	Level 4	High
Wu et al, ³² 2016, USA	Semi-structured interview	Cancer	42 cancer patients and 12 healthcare professionals (doctors and nurses)	Evaluate participants views of a webtool that was designed to allow PRO use in clinical practice.	Patients and healthcare professionals recommended having PRO score directionality be consistent, and more explanation of the score meaning. Healthcare professionals also recommended including if the score indicates better or worse health.	Q1	Level 4	High

Note. JBI = Joanna Briggs Institute. PRO = Patient reported outcome. PROM = Patient reported outcome measure. USA = United States of America. UK = United Kingdom.

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Table 2. Summary of different PRO data presentation formats.

Graphical Format	Summary	Healthcare professional preference
Tables with numerical data	Presentation of data in tables is considered more neutral and needing less explanation for interpreting the meaning of the data than when presented in graphs. Tables with large amounts of data may be perceived as cluttered and lacking visual clarity, making them difficult to read. ^{25 28}	+/- Mixed
Use of icons/pictographs	Most healthcare professionals find tables with icons to be insufficient and lacking transparency. ^{25 27} This is the inverse to patients, who prefer such displays due to their simplicity. ²⁸	- Negative
Line graphs	Line graphs are the preferred approach for presenting individual patient PRO scores over time. ^{6 11 19 27 29 34} However, if there are too many outcome variables, the line graph may become difficult to interpret. ³¹ The recommended maximum number of lines that should be displayed within a single graph is four. ¹⁹	+ Positive
Bar graph	Bar graphs are widely liked as they are clear and facilitate comparison. ^{19 27} They can also easily include additional information (e.g. confidence intervals and descriptive labels). The use of confidence intervals should be accompanied by a written explanation to facilitate interpretation of the data. ²⁵ To reduce confusion, the recommended maximum number of bars within a single graph should be six. ¹⁹	+ Positive
Funnel plots	Funnel plots can provide a good overview, but also contain a lot of information. Those unfamiliar with funnel plots may find them confusing. ^{25 28 31} As such, the use of funnel plots should be accompanied by a detailed explanation of how to be interpreted.	+/- Mixed
Caterpillar plots	Caterpillar plots are less familiar to healthcare professionals and patients than bar graphs. ^{25 28} Though caterpillar plots are clearer than bar graphs containing confidence intervals, and can facilitate rapid comparisons between larger amounts of groups. ^{25 31}	+ Positive
Spider plots or radar chart	Healthcare professionals who are unfamiliar with spider plots may find them confusing and lacking clarity. ²⁵ Spider plots also make displaying additional information such as confidence intervals or statistical significance difficult. ²⁵	- Negative
Pie Charts and Stacked Bar Graphs	Pie charts and stacked bar graphs are both reasonable formats for presenting proportions visually, especially when there are big differences. ^{11 31} Healthcare professionals are more accurate at interpreting stacked bar graphs compared with pie charts, ³¹ while patients can interpret pie charts more accurately. ²	+ Positive

6 Box 1. Summary of basic guiding principles

Recommendations to guide best practice in PRO data feedback to clinicians:

- Reporting PRO data back to clinicians should be done in a simple format that is easy to read to reduce the chance of misinterpretation.³³
- Features that may be used to facilitate simple reporting include: reducing the number of metrics presented within a report and minimising page counts.³³
- PRO reporting should avoid mixing the directions of scores that are displayed. Exceptionally clear labelling, titling and annotations should also be used to increase interpretability.^{2 11 29}
- The use of coloured arrows (e.g. green for better scores and red for worse scores) may enhance clinicians' interpretation of PRO scores presented across different domains.²⁹
- Clinically significant differences and confidence intervals should be included where possible. There is a move away from reporting just the *p*-value.^{6 11}

Recommendations for optimal data presentation formats:

- The choice of which graphical format to use to display the PRO data, will depend on the type of data (i.e. single outcome/multiple outcomes, single time point/multiple time points, amount of data to display etc.) and the intended purpose of the data.¹⁹
- Line graphs and bar graphs are preferred and reduce the chance of misinterpreting the data.^{19 27}
- The maximum number of bars presented within a bar graph should be 6, while the maximum number of lines within a line graph should be 4.¹⁹
- More complex displays such as funnel plots or caterpillar plots should be accompanied by a description of how to interpret the graph.²⁵

Recommendations to address barriers and enablers associated with feedback and reporting of PROs:

- The inclusion of clinical/local champions is critical to generate buy-in from the clinical community (Aspex Consulting, Evaluation Framework and Initial Appraisal of PROMS: Final Report, personal communications, 2018).
- PROs should be reported in a way that can be directly translated into specific actions to guide clinicians to respond to concerning results.^{21 23}
- Training and education are needed to improve the clinician's ability to interpret PRO data, to integrate the use of PROs into their routine practice, and to respond to concerning results.^{38 41}
- The optimal time intervals for PRO feedback needs to be determined. One suggested timeframe for audit and feedback to clinicians is 1 to 4 times a year.³¹

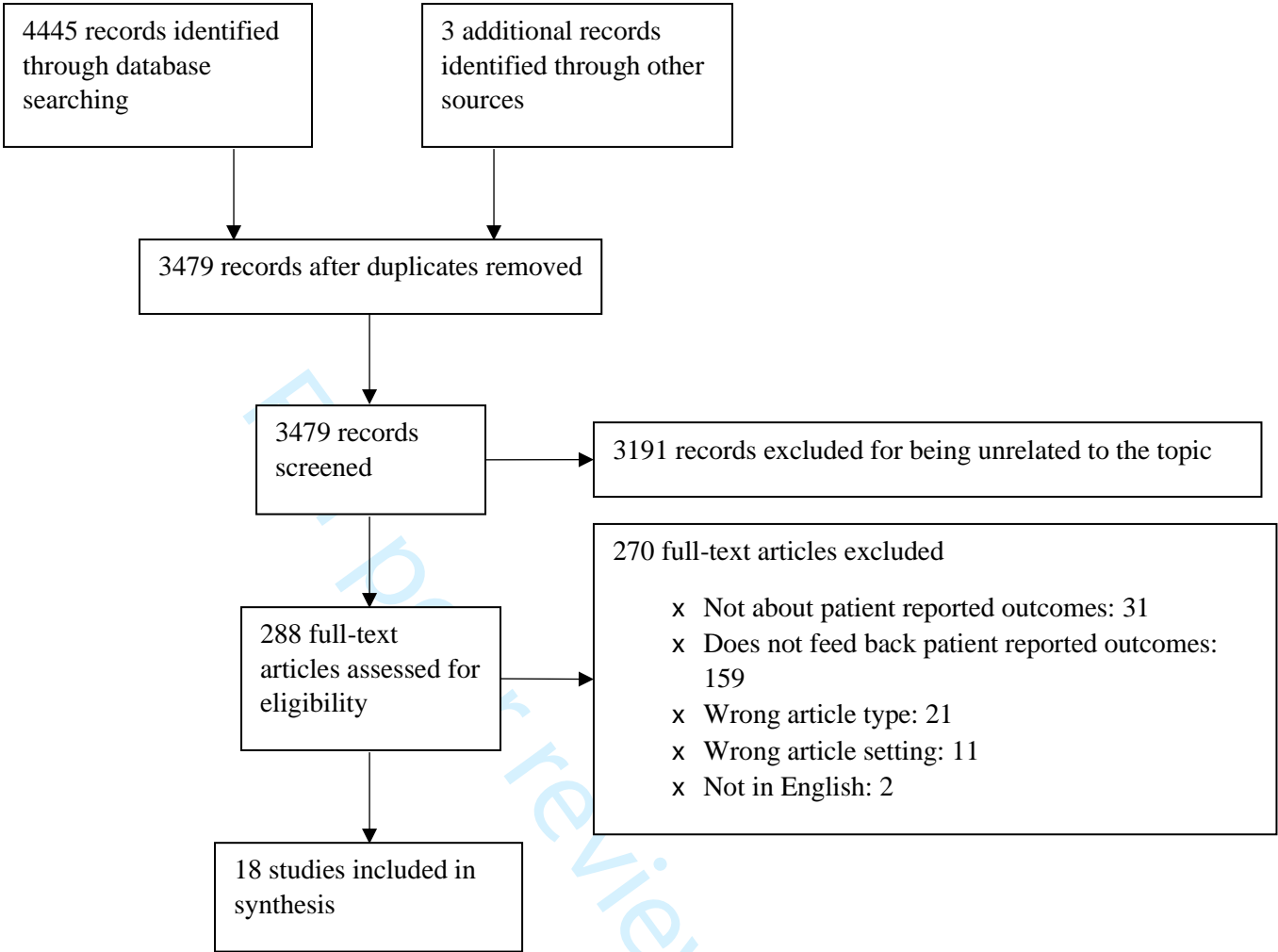


Figure 1. PRISMA flow chart illustrating findings from the academic literature search¹⁸

Supplemental Table 1. Breakdown of academic literature search strategy and key words.

Database	Search string	Results
Embase	Patient-reported outcome measures Patient reported outcomes PROMs PROM PROs PRO 1 or 2 or 3 or 4 or 5 or 6 – 213251 results Patient-centered care Patient centred care Health care policy Value based health care Low value care Quality of care Health care quality Quality improvement 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15– 112842 results Feedback Audit Review Benchmark Practice data Hospital* data Dashboard Dash board Public* report* 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 – 7 and 16 and 26 - Limit 27 to (English language and yr="2009-Current")	905
Ovid Medline	1. Patient-reported outcome measures 2. Patient reported outcomes 3. PROMs 4. PROM 5. PROs 6. PRO 7. 1 or 2 or 3 or 4 or 5 or 6 – 213251 results 8. Patient-centered care 9. Patient centred care 10. Health care policy 11. Value based health care 12. Low value care 13. Quality of care 14. Health care quality 15. Quality improvement 16. 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15– 112842 results 17. Feedback 18. Audit	390

	19. Review 20. Benchmark 21. Practice data 22. Hospital* data 23. Dashboard 24. Dash board 25. Public* report* 26. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 – 27. 7 and 16 and 26 – Limit 27 to (English language and yr=“2009-Current”)	
Scopus	TITLE-ABS-KEY ("Patient reported outcome measures" OR "patient reported outcomes" OR "PROMs" OR "PROM" OR "PROs" OR "PRO") AND ("patient centered care" OR "patient centred care" OR "health care policy" OR "value based health care" OR "low value care" OR "quality of care" OR "health care quality" OR "quality improvement") AND ("feedback" OR "audit" OR "review" OR "benchmark" OR "practice data" OR "hospital* data" OR "dashboard" OR "dash board" OR "public* report") AND (LIMIT-TO (DOCTYPE , "ar") OR LIMIT-TO (DOCTYPE , "re") OR LIMIT-TO (DOCTYPE , "ed") OR LIMIT-TO (DOCTYPE , "cp")) AND (LIMIT-TO (SUBJAREA , "MEDI") OR LIMIT-TO (SUBJAREA , "HEAL")) AND (LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009)) AND (LIMIT-TO (LANGUAGE , "English"))	2896
Web of science	TOPIC: (("patient reported outcome measures" OR "patient reported outcomes" OR "PROMs" OR "PROM" OR "PROs" OR "PRO") AND ("patient centered care" OR "patient centred care" OR "health care policy" OR "value based health care" OR "low value care" OR "quality of care" OR "health care quality" OR "quality improvement") AND ("feedback" OR "audit" OR "review" OR "benchmark" OR "practice data" OR "hospital* data" OR "dashboard" OR "dash board" OR "public* report")) Timespan: 2009-2019	220

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3-4
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	4
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	4
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	4,5
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	4,6
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplementary table
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	5
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	5,6,7
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	5,6
Critical appraisal of individual	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe	6

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
sources of evidence§		the methods used and how this information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	7
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	7, Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Table 1
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Table 1
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Table 1
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Table 1, 8-14
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Box 1, 14-16
Limitations	20	Discuss the limitations of the scoping review process.	16
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	17
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	2

JB1 = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*. 2018;169:467–473. doi: 10.7326/M18-0850.



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Feedback of Patient Reported Outcomes to healthcare professionals for comparing health service performance: A scoping review

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Feedback of Patient Reported Outcomes to healthcare professionals for comparing health service performance: A scoping review.

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26
27 **Author Contribution**

28 All authors were involved in the planning of the project. Shaun Hancock, Olivia Ryan, and
29 Violet Marion were involved in the search strategy, extraction and synthesis of data, and
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Feedback of Patient Reported Outcomes to healthcare professionals for comparing health service performance: A scoping review.

Abstract

Objective: Patient reported outcomes (PROs) provide self-reported patient assessments of their quality of life, daily functioning, and symptom severity after experiencing an illness and having contact with the health system. Feeding back summarised PRO data, aggregated at the health-service level, to healthcare professionals may inform clinical practice and quality improvement efforts. However, little is known about the best methods for providing these summarised data in a way that is meaningful for this audience. Therefore, the aim of this scoping review was to summarise the emerging approaches to PROs ‘service-level’ feedback to healthcare professionals.

Setting: Healthcare professionals receiving patient reported outcome data feedback at the health-service level.

Data sources: Databases selected for the search were Embase, Ovid Medline, Scopus, Web of Science, and targeted web-searching. The main search terms included: ‘patient-reported outcome measures’, ‘patient-reported outcomes’, ‘patient-centred care’, ‘value-based care’, ‘quality improvement’ and ‘feedback’. Studies included were those that were published in English between January 2009 and June 2019.

Primary and secondary outcome measures: Data were extracted on the feedback methods of PROs to patients or healthcare providers. A standardised template was used to extract information from included documents and academic publications. Risk of bias was assessed using Joanna Briggs Institute Levels of Evidence for Effectiveness.

Results: Overall, 3480 articles were identified after de-duplication. Of these, 19 academic publications and 22 documents from the grey literature were included in the final review. Guiding principles for data display methods and graphical formats were identified. Seven

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major factors that may influence PRO data interpretation and use by healthcare professionals were also identified.

Conclusion: While a single best format or approach to feedback PRO data to healthcare professionals was not identified, numerous guiding principles emerged to inform the field.

Strengths and limitations of this study

- This scoping review provides a novel summation of the published and grey literature of the guiding principles for effectively feeding back Patient Reported Outcome data to healthcare providers.
- The search strategy was broad, including individual patient level, health-service level, and system level reporting of Patient Reported Outcome data to ensure no relevant articles were missed.
- Two reviewers conducted the literature syntheses, with one person completing the academic synthesis and one person completing the grey synthesis. Using a standardised data extraction process for both types of literature, the findings from this review inform the rapidly growing fields of improvement science and implementation research related to health-service level reporting of aggregate Patient Reported Outcome data to healthcare professionals.

INTRODUCTION

There is growing interest in the use of Patient Reported Outcomes (PROs) for all aspects of health care. This is because information available from administrative and routinely collected clinical data do not provide a comprehensive picture related to health outcomes once patients leave hospital.¹ PROs are outcome data collected directly from patients about their health and the potential impacts of treatments or management within the health system.² PROs are differentiated from Patient Reported Outcome Measures (PROMs), which are the instruments or survey tools used to obtain PROs.³ Reporting of PRO data can occur at the individual patient level and be used to inform decisions about patient-centred care, or at the aggregated service and system levels, and may be used to assess and compare organisational performance or for population surveillance.^{4 5}

PROs were originally developed for use in research, such as comparative effectiveness studies and clinical trials.^{6 7} However, the value of using PROs to inform clinical practice has since been realised.^{8 9} PROs have evolved in a somewhat disparate manner between different countries, with each country aligning the use of PRO collections with a slightly different emphasis.⁵ For example, in England the focus of PRO collections is on hospital performance in selected elective surgeries, whereas in the Netherlands and Sweden, collection of PROs predominately occurs through disease-specific Clinical Quality Registries (CQRs).⁵

Healthcare professionals have reported challenges in relation to interpreting the meaning and implications of PRO data.^{6 10} These challenges can arise due to the variation by which PRO data are used, scored, and reported.⁶ Methods for optimising the feedback of PRO data to healthcare professionals is an emerging field of research.^{2 11 12} Currently, little is known about the best methods for providing summarised PRO data in a way that is meaningful for health care providers. To the best of our knowledge, there is currently little

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empirical evidence available to support best practice in the feedback methods for PRO data, particularly at the health-service level.

The aim of this review was to investigate the emerging approaches to the feedback and report PRO data to healthcare professionals, in order to understand how to increase engagement and uptake of these data. Three questions were used to explore this aim: (1) What is the existing evidence on best practice in the readability and feedback of PRO data to healthcare professionals? (2) What PRO data presentation formats have the most utility for healthcare professionals? (3) Are there factors that influence PRO data interpretation or use in clinical practice?

METHODS

The rapid scoping review was undertaken by a research team with clinical expertise (nursing, allied health, psychology) from the Australian Stroke Clinical Registry (AuSCR) with over ten years’ experience collecting and reporting generic and disease specific PROs in consultation with end-users who work in hospitals or government¹³. Consultation was undertaken with government representatives from the Victorian Agency for Health Information including author MPK, who are collecting PROs data on an ongoing basis from health services, including hospitals. Weekly team meetings were held to ensure a standardised screening and data extraction process whereby information about papers under consideration were discussed based on the information gathered by author SH (Honours, Psychology) or OR (Honours, Health Information Management) using the relevant data extraction tool.

The methods used for the review (including inclusion criteria, search strategy, extraction and synthesis) were specified in advance in an unpublished protocol, based on the Joanna Briggs Institute Guidelines for conducting a scoping review.¹⁴ Two search strategies were used. The first covered the academic, peer reviewed literature and the second covered

grey literature (such as government reports and policy documents). Different strategies were used to search the two sources of evidence. Rapid review methods using recommended approaches by the Cochrane collaboration¹⁵ were drawn upon for this scoping review. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) was used for report results.¹⁶

Academic Literature Search

For the academic literature, four databases were selected , including: Embase; Ovid Medline; Scopus; and Web of Science. These databases were chosen to maximise the scope of articles that were retrieved. The search included phrases related to the following terms and concepts: patient-reported outcome measures, patient-reported outcomes, patient centred care, value-based care, quality improvement, feedback, audit, and dashboard. A full list of search terms and the combinations used is available in Supplemental Table 1.

Studies included were those that were published in English between January 2009 and June 2019, where the feedback methods of PROs to patients or healthcare providers were described. Studies prior to 2009 were excluded to accommodate a contemporary, timely and comprehensive summary. Abstract booklets, conference abstracts, and newsletters, were excluded. Publications for studies that were pilot/development/protocol projects, focused on testing a PRO measurement tool, or in which PROs were used as the endpoint outcome for an observational or comparative-effectiveness study were excluded. Further, studies related to primary care, emergency care or non-acute conditions (e.g. surgical interventions or interventional devices) were also excluded. The initial search was broad to include studies related to individual patient-level feedback of PRO data to ensure no relevant articles were missed, however, the synthesis of the literature focussed primarily on health-service level reporting of aggregate PRO data to healthcare professionals.

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All references identified from these searches were downloaded and imported into Covidence software.¹⁷ Following removal of duplicates, the screening process involved one reviewer (SH, Honours Psychology) reading the titles and abstracts of each article to determine relevance using the inclusion and exclusion criteria outlined above. The full text of the relevant articles was then assessed by one reviewer (SH), with a second reviewer (CW, Masters, Health Information Management) conducting an independent assessment on a subset of the articles to ensure standardisation. If any disagreements for study eligibility arose, these were resolved through discussion and consensus between the two reviewers. If disagreements were unable to be resolved using this approach, the article was to be reviewed by a third reviewer to determine eligibility. This latter process was not required. SK provided training for the team in conducting a review, as a past Cochrane reviewer. Additional support was provided by SK and DAC, who have extensive experience conducting literature reviews.¹⁸⁻²⁰

Academic Literature Data Extraction and Charting

Data from the included academic literature were systematically extracted using a predetermined data extraction template by one reviewer (SH). The extraction template was developed by the review team in consultation with VAHI representatives. The template was then piloted and adapted as necessary. The final extraction template included: characteristics of study participants (including age, profession, area of practice, and number of participants), type of article, which PROs were used, the purpose of the feedback, and the findings of the study. Findings were extracted from all included academic literature by selecting those text passages and outcomes that related to each research question. The academic data extraction tool is available in appendix 1.

Level of Evidence and Critical Appraisal of the Academic Literature

The methodological design of all included articles was assessed according to the Joanna Briggs Institute Levels of Evidence for Effectiveness²¹ by SH, in order to assess the

quality and rigour of the evidence. Studies were assigned Level 1 (experimental), Level 2 (quasi-experimental), Level 3 (analytical), Level 4 (descriptive) or Level 5 (expert opinion). Further, the included research articles were appraised for strength of evidence by one reviewer (SH) using the critical appraisal tools from the Joanna Briggs Institute.²² Each article was assigned a rating of quality based on how many of the criteria the article fulfilled (e.g. “Were the criteria for inclusion in the sample clearly defined?”). Studies that met all criteria were rated as very high, studies that met 80% or more of criteria were rated as high, studies that met 60% or more, 40% or more, and less than 40% of the criteria were rated as moderate, low, and very low respectively. While critical appraisal assessments are not mandatory for conducting a scoping review,¹⁴ given the breadth of studies and their designs that we were anticipating we felt that an assessment of the article quality was relevant to considering the evidence we were extracting.

Grey Literature Search

We elected to use similar methods to those of a previous PRO literature search conducted by Williams and colleagues (2016).⁵ The grey literature component of our search included Google searches, targeted website searches and snowballing of reference lists, where appropriate. The first ten pages of results retrieved from each Google search were reviewed.⁵ The following search terms were used:

- ‘Use of Patient-Reported Health Outcome Measures in (country)’
- ‘Feedback of Patient-Reported Health Outcome Measures in (country)’
- ‘patient-reported outcome measure + feedback + use in (country)’
- ‘Benchmarking of Patient-Reported Health Outcome Measures in (country)’

Due to the limited timeframe for completing the study, the grey literature search was restricted to seven countries. The countries included in the Google searches were Sweden, the

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Netherlands, Finland, Canada, United Kingdom, United States of America (USA) and Australia. The selection of these countries was based on the prior research of William and colleagues (2016)⁵ which found substantial examples of the use of PROs within these regions. The websites of relevant leading organisations (i.e. health agencies, government organisations, professional organisations, special interest groups, research institutes and universities) were also searched. For example, the websites of organisations such as: The Institute for Healthcare Improvement (IHI), The International Consortium for Health Outcomes Measurement (ICHOM) (i.e. the United States), The Dutch Institute for Clinical Auditing (DICA) (i.e. The Netherlands) and The Organisation for Economic Co-operation and Development (OECD) were searched. Further, the websites and Annual Reports of national clinical quality registries that were known to collect and report PRO data were also searched.

Similar to the inclusion criteria applied for the academic literature, materials that were published in English between 2009 and 2019 were included. Internet page entries without PROs data; focussed on single-centre studies or testing PRO instruments were excluded. We also excluded literature related to primary care, emergency care or surgical interventions/devices; did not relate to the target country; or were duplicate entries were excluded.

Grey Literature Data Extraction and Charting

A second data extraction template was used for the grey literature. Data from the included grey literature were systematically extracted using a predetermined data extraction template by two independent reviewers (OR, Honours, Health Information Management; and VM, Nursing). Similar to the methods used for the academic literature template, the grey literature data extraction template was developed by the review team in consultation with VAHI

representatives. The final template included information on: the type of document, title, name of the organisation that produced the document, background PROM information, PRO data display features, PRO data feedback mechanism(s) the identified barriers and enablers to PRO uptake among clinicians, and PRO data issues (e.g. statistical/analytical methods). The grey literature data extraction tool is available in appendix 2.

Collating and Synthesising Results

The data within the extraction forms used for the academic and grey literature templates were sorted according to which research question they contributed to answering. The findings were then grouped into themes (e.g. missing data, healthcare professional education and training) . Once established, each theme was presented and discussed between SH, OR and VM. The preferences of PRO data formats among healthcare professionals determined in the current study was summated from all articles that described PRO data formats preferences. An inductive approach was used to analyse the qualitative findings to address the research question related to factors that influence PRO data interpretation or use, whereby themes were developed by studying the findings and were considered how they fit within the developing themes.

Patient and Public Involvement

No patients were involved in setting the review questions or in the design of the initial protocol and overall study. No patients were asked to advise on the interpretation and write up of the results. This study forms the first component of a broader program of work initiated by VAHI and stakeholder engagement methods were used in the subsequent stages of the project.

RESULTS

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The initial search resulted in the identification of 4445 academic articles. Following the removal of duplicates 3480 unique articles remained, nineteen of which were included in the final review. Figure 1 summarises the academic literature search using a PRISMA flowchart.²³ The publication characteristics, level of evidence and quality appraisal of the included academic literature are available in Table 1. Research methods included two reviews,^{24 25} three case studies,^{12 26 27} two consensus panels,^{11 28} one opinion article,²⁹ and 11 observational studies.^{2 6 30-38} According to the Joanna Briggs Institute Levels of Evidence for Effectiveness,²¹ the nineteen included studies were classified according to the following levels: 1 (n=0), 2 (n=1), 3 (n=3), 4 (n=12), 5 (n=3). The studies were primarily conducted in United States of America, Australia, Canada, and European countries. From the grey literature search, 103 materials were determined to be topically relevant and were scanned for further information. Of these, a total of 22 were included in the final review, including 16 reports,^{1 3-5 39-49}(Aspex Consulting, Evaluation Framework and Initial Appraisal of PROMS: Final Report, personal communications, 2018) two book chapters,^{50 51} one dissertation,⁵² one forum proceeding document,⁵³ , one users guide,⁵⁴ and one research report.⁵⁵The summary of the included grey literature is available in table 2.

<insert Figure 1 here>

<insert Table 1 here>

<insert Table 2 here>

The following results are presented by research question.

1. What is best practice in the readability and feedback of PRO data to healthcare professionals?

Overall, the current evidence base provides some general guidance but inadequately describes specific optimal data display methods for the feedback of PRO data to healthcare professionals. From this review, several issues related to the reporting of PRO data to health professionals were explored and summarised, and recommendations identified to address these issues are provided below.

Authors from two publications suggested that in order to engage health professionals in reviewing PRO data, PRO reports need to be simplistic and easy to read.^{24 25} Suggested modifications to improve readability of feedback interventions included: reducing the number of metrics (i.e. outcomes) presented within a report, minimising page counts, avoiding 3-dimensional graphical elements, uncluttering reports to increase readability and including instructions where they will be needed.²⁹

Six publications addressed the issue of directionality of PRO scores in graphical displays.^{2 11 12 35 38 55} A consensus panel found that there was no intuitive interpretation of symptom scores, with some people expecting higher scores to mean 'better' and other people expecting higher scores to mean 'more' of the symptom (and therefore worse).¹¹ Healthcare professionals interpretation accuracy has been demonstrated to be greater for line graphs when higher scores indicated 'better' rather than indicating 'more'.⁵⁵ Despite these results, caution should be taken when modifying the directionality of PROs in order for all symptom scores to have the same directionality, due to potential confusion associated with inconsistencies across instruments.¹¹ One suggestion to avoid potential confusion is to provide a label to denote 'better' alongside the chart to indicate the directionality of the PRO,^{2 38} or use coloured arrows; green for better scores, and red arrows for worse scores.³⁵

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Further, the provision of a written explanation of the PRO score alongside the graph, has also been recommended to assist with interpretation.²⁹ Written explanations are particularly valuable for complex graphical displays.^{31 37} Another suggestion is to include descriptive labels (e.g. mild/moderate/severe) alongside the chart, assuming data to support the use of these thresholds are available.^{11 27} The use of ‘traffic-light’ colours to colour-code the thresholds has also been recommended to allow a quick and easy review.^{30 34-36}

Displaying a reference population to use as a comparison was addressed in 4 publications.^{3 11 37 48}. Reference populations, such as national averages or relevant norm information for peer groups, can help provide context for the interpretation of the PRO scores,³⁷ provided these data are available.¹¹ However, there is a need to balance the complexity of presenting additional data and the healthcare professionals’ ability to understand the data.¹¹ Furthermore in an exploratory study participants warned that providing comparison data can have unintended consequences, such as negative comparisons leading to reputational damage when the health service or healthcare professional is reported to be lesser performing in their PROs results.³⁷

A cross-sectional mixed methods study in oncology reported that healthcare professionals indicated a preference towards the inclusion of statistical details for PRO data.⁶ There is a move away from reporting the p-value alone to illustrate statistical significance, and instead the use confidence intervals is encouraged.^{6 11} The clinically important difference should also be included within the graphical representation of the PRO results, where appropriate.^{11 25} Though an asterisk is not recommended to indicate clinically important differences, as that symbol is commonly used to indicate statistical significance.¹¹ Patients can find the inclusion of clinically important differences confusing,⁶ but it is valuable for them to know if the difference matters.¹¹

2. What PRO data presentation formats have the most utility for healthcare professionals?

There are many different formatting approaches that have been used to display PRO results. Table 3 provides a summary of different formats that have been utilised to display PRO data, as well as an indication of the preference among healthcare professionals. Line graphs and bar graphs were identified as the most familiar and preferred format among healthcare professionals for comparing and reviewing their service.

<insert Table 3 here>

3. Are there factors that influence PRO data interpretation or use in clinical practice?

Within the current body of literature several barriers and enablers associated with the use and uptake of PROs among healthcare professionals have been identified. However, the evidence base addressing these proposed challenges, or explicit recommendations to enable successful adoption of PROs among healthcare professionals, is limited.^{1 53} We identified seven factors that influence the interpretation of PROs: missing data, government and local leadership, healthcare professional education and training, engaging healthcare professionals to overcome resistance to change in clinical practice, casemix adjustment, interoperability of information and communication technology (ICT) systems, and frequency/timeliness of feedback.

Missing data.

Missing data poses a challenge with analysis and reporting of PRO results. Missing PRO data may be unavoidable due to a multitude of reasons. There may be specific population groups with missing PRO responses, or sensitive and difficult questions that may be omitted.⁵⁰ Consequently, these instances may result in scepticism about completeness of the data among healthcare professionals.⁵²

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Achievement of high participation and completion rates at follow-up, both individually and at the aggregate level influences overall usefulness of PRO data.³⁹ However, due to the complex nature of PROs and their inevitable incompleteness in certain cases, strong evidence through a statistical analysis plan may assist in ensuring the resulting analyses and reports are unaffected by missing data.⁵⁰

The role of government and local leadership.

It has been reported that ‘top-down’ approaches to PRO implementation whereby government or management is driving the implementation process and performing the assessment and taking actions based on the rules, may be met with resistance from healthcare professionals.⁴ These endeavours can be complemented with ‘bottom-up’ approaches where PRO implementation is clinically driven and is more focused on quality improvement.⁴ The use of the data from these collection approaches can be reported back at the micro level (to inform decision for individual patient care), as well as the meso level (to assess performance of services and quality improvement) or the macro level (to asses healthcare systems).^{4 5} Importantly, the most evidence for effectiveness of PRO feedback exists at the meso level.⁵

Further, clinical/local champions and stakeholder initiatives are crucial to enhance healthcare professionals’ engagement with collecting and use of PRO data.⁵³ Specifically, clinical champions may contribute to broader dissemination and use of PRO data among clinical units or within health services (Aspex Consulting, Evaluation Framework and Initial Appraisal of PROMS: Final Report, personal communications, 2018).

Healthcare professional education and training.

Healthcare professionals education and training was addressed in nine publications.^{32 39 41 42 45 49 51 54 55} Healthcare professionals may not understand PRO data or know what to do with the results.^{39 49} There is a need to increase PRO-specific training and education to aid healthcare professionals’ ability to; interpret PRO data, integrate the use of PROs into clinical practice,

and respond to concerning PRO results.^{41 51} There is currently no recommendation for how to direct healthcare professionals to use and interpret PRO data or for how to respond to concerning results in a standardised, clinically appropriate manner.^{39 54} For example, our review found the need for disease management pathways to be developed as a resource to respond to issues identified through PRO results.⁵⁴ Implementation of a PRO training course has been demonstrated to improve attitudes and self-efficacy from healthcare professionals towards PRO data within the child mental health services.³²

Engaging healthcare professionals to overcome resistance to change in clinical practice.

There may be a lack of buy-in among the clinical community when healthcare professionals are uncertain or lack confidence in understanding how PRO results could be used to improve their clinical practice.⁴² As such, PROs should be implemented in a way that can be directly translated into specific actions for healthcare professionals, with clear recommendations on how to respond to PRO scores in clinical settings.^{26 28} Additional recommendations to improve healthcare professional buy-in include: co-designing data display formats and information content with healthcare professionals' input to ensure the formats meet their needs,^{25 39 49} and showcasing benefits to help health professionals see the merits of using PRO data.^{30 47}

Analyses that include adjustment for differences in patient characteristics (casemix adjustment).

Due to the differing characteristics of patients admitted to different health services, comparing outcomes between hospitals without casemix adjustment may be misleading.⁵³ Casemix adjustments are particularly important to healthcare professionals.⁵³ Casemix adjustment uses statistical models to account for known variables that affect health (such as age, gender, ethnicity, symptom severity, and socio-economic background) to predict what each hospital's outcomes would be for a standard patient or population.¹ The development of

casemix adjustment methods for PRO data are a widely recognised challenge in the field.^{1 48}

⁵³ For example, patients may be influenced by cultural, development or personality differences, contextual factors or life circumstances; and different health experiences or events when interpreting and responding to questions related to their health.⁵³ Importantly, casemix adjustment for PROs needs to be disease/condition-specific, since demographic factors that may influence patients’ responses to PROs are likely to vary across patient cohorts and clinical settings.⁴² Published evidence related to the development of casemix adjustment methods for PRO data is limited. Further development and refinement of robust casemix adjustment methods is required to guide meaningful interpretation and use of PRO data.^{1 43 53}

Interoperability of Information and Communication Technology (ICT) systems.

A lack of efficient, interoperable health information systems and robust data governance frameworks are a significant barrier to integration and reporting of PROs.^{44 48} ICT system interoperability issues prohibit patient-level linkage between datasets, impacting upon the ability to conduct risk-adjustments and draw meaningful conclusions from some PRO collections.⁴⁸

Frequency/timeliness of feedback.

The frequency or timelines of PRO feedback was addressed in 10 publications.^{3 5 29 30}

^{37 45-47 52 53} Perceived time lags associated with PRO data feedback, such as reports fed back annually, may lead to information being discounted as irrelevant.^{29 45 53} One solution is to routinely report PRO results to healthcare professionals or provide the capacity for clinical teams to continuously retrieve and review their own data.^{46 52} Conversely, too much feedback could result in ‘alert fatigue’, which may lead healthcare professionals to ignore the PRO results.³⁰ Despite reporting delays as a known barrier to healthcare professionals uptake of PROs, optimal intervals for feedback have seldom been investigated in this area.²⁹ One

suggested timing for audit and feedback to professional practice is 1-4 times a year for process and outcome indicators, but more frequently where there is greater possibility for improvement.³⁷

A summary of the overall prevailing consensus-based guiding principles are outlined in Box 1.

<insert box 1>

DISCUSSION

PRO data may be used to improve the safety and quality of healthcare, but in order to achieve this, it is critical that feedback methods are optimised. This scoping review provides a novel summation of the published and grey literature of the guiding principles for effectively feeding back Patient Reported Outcome data to healthcare providers. The overall synthesis of the literature revealed various issues that provide opportunities to advance this field.

What constitutes ‘best practice’ feedback for PROs is not yet firmly established. Despite this gap in the evidence, we were able to highlight multiple prevailing consensus-based approaches.

Studies on the feedback of PRO data are limited, however there is a large body of literature that informs graphical presentation of clinical data in general. This extensive research can inform understanding for the graphic representation of PROs. For example, similar graphical display features have been demonstrated in other forms of feedback to clinicians. In a review of quality dashboards used in clinical settings Dowding et al (2015)⁵⁶ found that most dashboards used the ‘traffic light’ colour coding in their displays to indicate what type of action is required. Converse to the suggestions made in the current review, Dowding et al (2015)⁵⁶ found that most dashboards used a table format to represent the data.

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Providing peer group data or benchmarking to enable comparison of current in clinical audit and feedback is also a common technique to improve engagement.^{57 58}

To facilitate the successful uptake of PRO data in clinical practice it is also recommended that a knowledge translation strategy is developed.⁵⁹ Identification of local barriers and enablers and the development of a theory-based integrative knowledge translation plan may support greater uptake and use of PRO data. Further, recommendations to improve knowledge translation have been identified in other types of clinical audit and feedback. The authors from multiple clinical audit and feedback studies have indicated that feedback is more effective when there is a local champion.^{60 61} The timeliness and actionability of the feedback are other factors that are consistently mentioned for effective clinical feedback.^{58 60 62 63} These findings are in line with the current study. Additional factors to improve the effectiveness of feedback include: providing feedback both verbally and in written format, and using feedback to decrease rather than increase certain behaviours.⁶⁰

There have also been several initiatives to develop guidance on communicating data in general, which can further inform the development of PRO data feedback. In a guide published by authors from the National Cancer Institute,⁶⁴ several suggestions for how to present data effectively are given, and multiple are in line with the current review, including: the use of labels and the use of colour. There are also additional suggestions including: the use of verbal qualifiers or metaphors to help explain the meaning of the numbers and rounding most decimals to the nearest whole number for ease of understanding. Simpson (2015) provides guidance for how to choose the appropriate graph type.⁶⁵ Nominal and ordinal data can be displayed using a pie graph or car chart, but interval and ratio data may have too many categories to be displayed in a pie chart. Further, box plots are best used to display variables that are not normally distributed.

Strengths of our review included that each reviewer used a pre-defined protocol and the information from the included literature was summarised using a template to ensure consistency. Despite our rigorous search strategy, several limitations deserve comment. Due to the available timeframe both the academic and grey literature search and screening process were largely conducted by a single reviewer. This may have resulted in selection and interpretation bias as some relevant literature may have been overlooked. Further, the grey literature search was limited to only seven countries. Despite this limitation, it is reasonable to assume that, much like the standards available for the presentation of data in other healthcare settings, the general guiding principles for PRO data feedback would be consistent across jurisdictions and between countries. Overall, we found limited high-quality published evidence related to optimal feedback methods and formats for PRO data. Our findings here suggest that there is a need for more rigorous testing of PRO feedback methods in the future.

Future directions

PROs represent a key building block required to move towards a health system that can assess the value of healthcare from a consumer's perspective (Paxton Partners, Patient-Reported Outcome Measures: Literature scan, personal communication, 2018). Little is known about the best way to feedback PRO data effectively to healthcare providers in considering the performance of their health services compared with peer services. We sought to summarise the current evidence base and use this information to facilitate a process to determine the best methods for future implementation of PROs reporting. As part of planned future work associated with the AuSCR^{13 66} we seek to test various formats based on our findings and extend the work conducted to date. AuSCR is one of the few national stroke clinical registries around the world to collect PROs.¹⁸ The outcome of this work will also inform the field and may be adopted by other Clinical Quality Registries.

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Conclusion

While ‘best practice’ feedback methods and presentation formats of PRO data to healthcare professionals are emerging, there remains many unanswered questions. The basic guiding principles and recommendations presented in the body of the current review draw upon the findings of the prevailing, consensus-based literature. Further research is required to determine what healthcare professionals perceive to be simple, easy-to-read and interpretable PRO reports for aggregated data. Healthcare professionals require support to interpret the data and should be part of the process of co-designing formats that will be the most meaningful to them. Our work here provides some guidance towards these efforts.

References

1. Canadian Institute for Health Information (CIHI). Health outcomes of care: An idea whose time has come. Ottawa, Ontario., 2012:1-52.
2. Brundage M, Blackford A, Tolbert E, et al. Presenting comparative study PRO results to clinicians and researchers: Beyond the eye of the beholder. *Quality of Life Research* 2018;27(1):75-90. doi: 10.1007/s11136-017-1710-6
3. Thompson C, Sansoni J, Morris D, et al. Patient-reported Outcome Measures: An environmental scan of the Australian healthcare sector. ACSQHC: Sydney, NSW: Australian Commission on Safety and Quality in Health Care, 2016:89.
4. Desomer A, Van Den Heede K, Triemstra M, et al. Use of patient-reported outcome and experience measures in patient care and policy: Belgian Health Care Knowledge Centre, 2018:1-151.
5. Williams K, Sansoni J, Morris D, et al. Patient-reported outcome measures: Literature review. ACSQHC: Sydney, NSW: Australian Commission on Safety and Quality in Health Care, 2016:1-91.
6. Brundage MD, Smith KC, Little EA, et al. Communicating patient-reported outcome scores using graphic formats: Results from a mixed-methods evaluation. *Quality of Life Research* 2015;24(10):2457-72. doi: 10.1007/s11136-015-0974-y
7. Santana MJ, Haverman L, Absolom K, et al. Training clinicians in how to use patient-reported outcome measures in routine clinical practice. *Quality of Life Research* 2015;24(7):1707-18. doi: 10.1007/s11136-014-0903-5
8. Ahmed S, Berzon RA, Revicki DA, et al. The use of patient-reported outcomes (PRO) within comparative effectiveness research: Implications for clinical practice and health care policy. *Medical Care* 2012;50(12):1060-70. doi: 10.1097/MLR.0b013e318268aaff

- 1
2
3 9. Prodinge B, Taylor P. Improving quality of care through Patient-Reported Outcome
4
5 Measures (PROMs): Expert interviews using the NHS PROMs Programme and the
6
7 Swedish quality registers for knee and hip arthroplasty as examples. *BMC Health*
8
9 *Services Research* 2018;18:1-13. doi: 10.1186/s12913-018-2898-z
10
11
- 12 10. Brundage M, Bass B, Jolie R, et al. A knowledge translation challenge: Clinical use of
13
14 quality of life data from cancer clinical trials. *Quality of Life Research*
15
16 2011;20(7):979-85.
17
18
- 19 11. Snyder C, Smith K, Holzner B, et al. Making a picture worth a thousand numbers:
20
21 Recommendations for graphically displaying patient-reported outcomes data. *Quality*
22
23 *of Life Research* 2019;28(2):345-56. doi: 10.1007/s11136-018-2020-3
24
25
- 26 12. Arcia A, Woollen J, Bakken S. A systematic method for exploring data attributes in
27
28 preparation for designing tailored infographics of patient reported outcomes. *eGEMs*
29
30 2018;6(1):1-9. doi: 10.5334/egems.190
31
32
- 33 13. Cadilhac DA, Lannin NA, Anderson CS, et al. Protocol and pilot data for establishing the
34
35 Australian Stroke Clinical Registry. *International Journal of Stroke* 2010;5(3):217-26.
36
37 doi: 10.1111/j.1747-4949.2010.00430.x
38
39
- 40 14. Peters M, Godfrey C, McInerney P, et al. Chapter 11: Scoping Reviews (2020 version).
41
42 In: Aromataris E MZ, ed. JBI Manual for Evidence Synthesis. Adelaide: JBI 2020.
43
44
- 45 15. Cochrane Training. Online learning 2019 [Available from:
46
47 <https://training.cochrane.org/online-learning> accessed June 2019.
48
- 49 16. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-
50
51 ScR): Checklist and Explanation. *Annals of Internal Medicine* 2018;169(7):467-73.
52
53 doi: 10.7326/M18-0850
54
55
- 56 17. Covidence systematic review software, [program]. Melbourne, Australia: Veritas Health
57
58 Innovation.
59
60

18. Cadilhac DA, Kim J, Lannin NA, et al. National stroke registries for monitoring and improving the quality of hospital care: A systematic review. *International Journal of Stroke* 2015;11(1):28-40. doi: 10.1177/1747493015607523
19. Campbell BCV, Ma H, Ringleb PA, et al. Extending thrombolysis to 4·5–9 h and wake-up stroke using perfusion imaging: a systematic review and meta-analysis of individual patient data. *The Lancet* 2019;394(10193):139-47. doi: [https://doi.org/10.1016/S0140-6736\(19\)31053-0](https://doi.org/10.1016/S0140-6736(19)31053-0)
20. Lynch E, Hillier S, Cadilhac D. When Should Physical Rehabilitation Commence after Stroke: A Systematic Review. *International Journal of Stroke* 2014;9(4):468-78. doi: 10.1111/ijss.12262
21. Joanna Briggs Institute. JBI Levels of Evidence 2014 [Available from: https://joannabriggs.org/sites/default/files/2019-05/JBI-Levels-of-evidence_2014_0.pdf accessed June 2019.
22. Joanna Briggs Institute Reviewer's Manual: The Joanna Briggs Institute 2017.
23. Moher D, Liberati A, Tetzlaff J, et al. Preferred Reporting Items for Systematic Reviews and Meta Analyses: The PRISMA Statement. *PLoS Med* 2009;6(7):e1000097. doi: doi:10.1371/journal.pmed1000097
24. Bantug ET, Coles T, Smith KC, et al. Graphical displays of patient-reported outcomes (PRO) for use in clinical practice: What makes a pro picture worth a thousand words? *Patient Education and Counseling* 2016;99(4):483-90. doi: <http://dx.doi.org/10.1016/j.pec.2015.10.027>
25. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: A systematic review of qualitative research. *BMJ Quality & Safety* 2014;23(6):508. doi: 10.1136/bmjqs-2013-002524

- 1
2
3 26. Forsberg HH, Nelson EC, Reid R, et al. Using patient-reported outcomes in routine
4 practice: Three novel use cases and implications. *Journal of Ambulatory Care*
5
6 *Management* 2015;38(2):188-95. doi: 10.1097/JAC.000000000000052
7
8
9
10 27. Oliver BJ, Nelson EC, Kerrigan CL. Turning feed-forward and feedback processes on
11 patient-reported data into intelligent action and informed decision-making: Case
12 studies and principles. *Medical Care* 2019;57 (Supplement 1):S31-S37. doi:
13
14 <https://dx.doi.org/10.1097/MLR.0000000000001088>
15
16
17
18
19 28. Jensen RE, Snyder CF, Basch E, et al. All together now: Findings from a PCORI
20 workshop to align patient-reported outcomes in the electronic health record. *Journal*
21 *of Comparative Effectiveness Research* 2016;5(6):561-67. doi: 10.2217/ce-2016-
22
23 0026
24
25
26
27
28 29. Brehaut J, Colquhoun H, Eva K, et al. Practice Feedback Interventions: 15 Suggestions
29 for Optimizing Effectiveness. *Annals of Internal Medicine* 2016;164(6):435-41. doi:
30
31 10.7326/M15-2248
32
33
34
35 30. Aiyegbusi OL, Kyte D, Cockwell P, et al. Patient and clinician perspectives on electronic
36 patient-reported outcome measures in the management of advanced CKD: A
37 qualitative study. *American Journal of Kidney Diseases* 2019;74(2):167-78. doi:
38
39 10.1053/j.ajkd.2019.02.011
40
41
42
43
44 31. Allwood D, Hildon Z, Black N. Clinicians' views of formats of performance comparisons.
45 *Journal of Evaluation in Clinical Practice* 2013;19(1):86-93. doi: 10.1111/j.1365-
46
47 2753.2011.01777.x
48
49
50
51 32. Edbrooke-Childs J, Wolpert M, Deighton J. Using Patient Reported Outcome Measures to
52 Improve Service Effectiveness (UPROMISE): Training clinicians to use outcome
53 measures in child mental health. *Administration and Policy in Mental Health and*
54
55
56
57
58
59
60

- Mental Health Services Research* 2016;43(3):302-08. doi: 10.1007/s10488-014-0600-2
33. Hartzler AL, IZard JP, Dalkin BL, et al. Design and feasibility of integrating personalized PRO dashboards into prostate cancer care. *Journal of the American Medical Informatics Association* 2016;23(1):38-47. doi: 10.1093/jamia/ocv101
34. Hildon Z, Allwood D, Black N. Making data more meaningful: Patients' views of the format and content of quality indicators comparing health care providers. *Patient Education and Counseling* 2012;88(2):298-304. doi: 10.1016/j.pec.2012.02.006
35. Kuijpers W, Giesinger JM, Zabernigg A, et al. Patients' and health professionals' understanding of and preferences for graphical presentation styles for individual-level EORTC QLQ-C30 scores. *Quality of Life Research* 2016;25(3):595-604. doi: 10.1007/s11136-015-1107-3
36. Talib TL, DeChant P, Kean J, et al. A qualitative study of patients' perceptions of the utility of patient-reported outcome measures of symptoms in primary care clinics. *Quality of Life Research* 2018;27(12):3157-66. doi: 10.1007/s11136-018-1968-3
37. van Overveld LFJ, Takes RP, Vijn TW, et al. Feedback preferences of patients, professionals and health insurers in integrated head and neck cancer care. *Health Expectations* 2017;20(6):1275-88. doi: 10.1111/hex.12567
38. Wu AW, White SM, Blackford AL, et al. Improving an electronic system for measuring PROs in routine oncology practice. *Journal of cancer survivorship : research and practice* 2016;10(3):573-82. doi: <http://dx.doi.org/10.1007/s11764-015-0503-6>
39. Nelson E, Hvitfeldt H, Reid R, et al. Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case studies from Dartmouth, Karolinska and Group Health. Lebanon, New Hampshire: The Dartmouth Institute for Health Policy and Clinical Practice, 2012:1-55.

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60

40. Duckett S, Cuddihy M, Newnham H. Targeting zero: Supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care - report of the Review of Hospital Safety and Quality Assurance in Victoria. Melbourne: State Government of Victoria; , 2016.

41. Clinical Oncology Society of Australia (COSA). Implementing monitoring of patient-reported outcomes into cancer care in Australia - A COSA Think Tank Report. Sydney, Australia: Clinical Oncology Society of Australia,, 2018.

42. Chen J. Integrated Care: Patient reported outcome measures and patient reported experience measures - A rapid scoping review. Sydney: NSW Agency for Clinical Innovation, 2015:1-116.

43. Franklin P, Chenok K, Lavalee D, et al. Framework to guide the collection and use of Patient-Reported Outcome Measures in the learning healthcare system. *Generating Evidence & Methods to improve patient outcomes* 2017;5(1):17. doi: 10.5334/egems.227

44. Batalden P, Corrigan, J, Harrison, W, Kerrigan, C and Øvretveit, J. Enabling uptake of a registry-supported care and learning system in the United States: A report to the Robert Wood Johnson Foundation from Karolinska Institutet and The Dartmouth Institute, 2014.

45. Canadian Institute for Health Information (CIHI). Patient-centred measurement and reporting in Canada launching the discussion toward a future state. Ottawa, Ont., 2017:1-46.

46. NSW Agency for Clinical Innovation. Patient Reported Measures – Program overview. Chatswood: ACI, NSW, 2018:18.

47. Canadian Institute for Health Information (CIHI). PROMs Background Document. Ottawa, Ontario, 2015:1-38.

- 1
2
3 48. World Economic Forum. Value in healthcare laying the foundation for health system
4 transformation. Cologny/Geneva, Switzerland: World Economic Forum, 2017:1-40.
5
6
7
8 49. Duckett S, Jorm C, Danks L. Strengthening Safety Statistics: How to make hospital safety
9 data more useful: The Grattan Institute, 2017.
10
11
12 50. Cappelleri J, Zou K, Bushmakina A, et al. Patient-Reported Outcomes: Measurement,
13 Implementation and Interpretation. Boca Raton, FL: CRC Press 2014.
14
15
16 51. Raine R, Fitzpatrick R, Barratt H, et al. Patient-reported outcome measures and the
17 evaluation of services. Challenges, solutions and future directions in the evaluation of
18 service innovations in health care and public health: National Institute for Health
19 Research 2016.
20
21
22
23
24
25 52. Peterson A. Learning and understanding for quality improvement under different
26 conditions - An analysis of quality registry-based collaboratives in acute and chronic
27 care. Jönköping University, 2015.
28
29
30
31
32 53. Canadian Institute for Health Information (CIHI). CIHI PROMs Forum Proceedings.
33 Ottawa, Ontario, 2015:41.
34
35
36 54. Aaronson N, Elliott T, Greenhalgh J, et al. User's Guide to Implementing Patient-
37 Reported Outcomes Assessment in Clinical Practice. Version 2: January 2015:
38 International Society for Quality of Life Research 2015:1-47.
39
40
41
42
43 55. Snyder C, Brundage M, Smith KC, et al. Testing Ways to Display Patient-Reported
44 Outcomes Data for Patients and Clinicians. Washington, DC: Patient-Centered
45 Outcomes Research Institute (PCORI), 2018:1-163.
46
47
48
49
50 56. Dowding D, Randell R, Gardner P, et al. Dashboards for improving patient care: Review
51 of the literature. *International Journal of Medical Informatics* 2015;84(2):87-100. doi:
52 <https://doi.org/10.1016/j.ijmedinf.2014.10.001>
53
54
55
56
57
58
59
60

57. Ray-Barruel G, Ullman AJ, Rickard CM, et al. Clinical audits to improve critical care: Part 2: Analyse, benchmark and feedback. *Australian Critical Care* 2018;31(2):106-09. doi: <https://doi.org/10.1016/j.aucc.2017.04.002>
58. Colquhoun H, Michie S, Sales A, et al. Reporting and design elements of audit and feedback interventions: a secondary review. *BMJ Quality & Safety* 2017;26(1):54. doi: 10.1136/bmjqs-2015-005004
59. Eilayyan O, Visca R, Zidarov D, et al. Developing theory-informed knowledge translation strategies to facilitate the use of patient-reported outcome measures in interdisciplinary low back pain clinical practices in Quebec: mixed methods study. *BMC Health Services Research* 2020;20(1):789. doi: 10.1186/s12913-020-05616-5
60. Ivers N, Jamtvedt G, Flottorp S, et al. Audit and feedback: Effects on professional practice and healthcare outcomes. *Cochrane Database of Systematic Reviews* 2012(6) doi: 10.1002/14651858.CD000259.pub3
61. Christina V, Baldwin K, Biron A, et al. Factors influencing the effectiveness of audit and feedback: nurses' perceptions. *Journal of Nursing Management* 2016;24(8):1080-87. doi: 10.1111/jonm.12409
62. Payne VL, Hysong SJ. Model depicting aspects of audit and feedback that impact physicians' acceptance of clinical performance feedback. *BMC Health Services Research* 2016;16(1):260-72. doi: 10.1186/s12913-016-1486-3
63. Hysong SJ, Best RG, Pugh JA. Audit and feedback and clinical practice guideline adherence: Making feedback actionable. *Implementation Science* 2006;1(1):9. doi: 10.1186/1748-5908-1-9
64. National Cancer Institute. Making data talk: A workbook. In: U.S. Department of Health and Human Services, ed. USA: National Institute of Health 2011.

- 1
2
3 65. Simpson SH. Creating a data analysis plan: What to consider when choosing statistics for
4 a study. *Can J Hosp Pharm* 2015;68(4):311-17. doi: 10.4212/cjhp.v68i4.1471
5
6
7
8 66. Cadilhac Dominique A, Andrew Nadine E, Lannin Natasha A, et al. Quality of acute care
9 and long-term quality of life and survival. *Stroke* 2017;48(4):1026-32. doi:
10 10.1161/STROKEAHA.116.015714
11
12
13
14
15
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Table 1. Characteristics of the included academic literature

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Aiyegbusi et al, ³⁰ 2019, UK	Semi-structured interviews and focus groups	Chronic kidney disease	12 patients with chronic kidney disease, and 22 healthcare professionals (nurses, psychologist, nephrologist, registrars and surgeons)	Thematic analysis of participants views on the use of a PROM system	Healthcare professionals suggested graphical representations of PROM feedback (rather than numeric), and to include “traffic light” colour-coding for quick and easy review. Healthcare professionals believed that "alert fatigue" from PROM feedback could be a barrier to use of PROM data, with the numerous alerts being provided to healthcare professionals encouraging them to ignore the PROM results.	Q1 Q3	Level 4	Moderate
Allwood et al, ³¹ 2013, UK	Structured focus groups	All healthcare areas	107 healthcare professionals (including consultants, junior doctors, nurses and allied health professionals)	Thematic analysis of participants comprehension and format preference for PROM data.	Healthcare professionals were generally positive about the use of bar charts and caterpillar plots for the display of PROM results. Opinions were mixed for the use of tables, funnel plots, and spider plots. Healthcare professionals found that tables with icons were insufficient.	Q1 Q2	Level 4	High
Arcia et al, ¹² 2018, USA	Case study	Unspecified	2 case studies of PRO feedback projects	Explore methods affecting the design decisions of PRO feedback projects	Summarises considerations that must be understood for the visualisation of PRO data, including the range and direction of scoring.	Q1	Level 4	Very low
Bantung et al, ²⁴ 2016	Integrated literature review, dates: 1999-2014	Oncology	9 included studies	Exploring the interpretation of graphic presentations of PRO data in clinical practice	HRQOL PROs can be accurately interpreted by healthcare professionals and patients; line graphs and bar charts were the most preferred format for PROs; patients prefer simple graphs, while healthcare professionals prefer simple graphs with confidence intervals	Q1 Q2	Level 4	High

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Boyce et al, ²⁵ 2014	Systematic review, dates: Up to 2012	All healthcare areas	16 included studies	Summarise qualitative studies that explore the experience of healthcare professionals using PROMs	Healthcare professionals value PROMs if they can be used to aid decision making. They appreciate graphical presentations that clearly depict clinically important changes. However, they can question whether the PROM data produced is an accurate reflection of care. Attitude towards the use of PROMs may be improved by engaging the healthcare professionals in the planning stage of PROMs introduction.	Q1 Q3	Level 4	High
Brehaut et al, ²⁹ 2016, Canada	Opinion	All healthcare areas	68 included studies	Identify suggestions for designing and delivering effective feedback interventions	Barriers: the use of unnecessary three-dimensional graphical elements which can clutter the display and bias the interpretation of the underlying information. Enablers: closely linking visual displays with summary messages, minimization of extraneous cognitive load for target audiences, the provision of short, actionable messages combined with optional detail and addressing the credibility of the data source used to produce the feedback.	Q1 Q3	Level 5	Low
Brundage et al, ⁶ 2015, USA	Survey followed by a semi-structured interview	Cancer	50 patients with cancer, and 20 oncology healthcare professionals (doctors and nurses)	Explore interpretation accuracy, ratings of ease-of understanding and usefulness of graphical formats. The interview explored helpful and confusing format attributes.	Both patients and healthcare professionals prefer line graphs across group-level data and individual-level data formats (compared with bar charts and cumulative distributions), but healthcare professionals prefer greater detail (i.e. statistical details) for group-level data.	Q1 Q2	Level 3	Moderate

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Brundage et al, ² 2018, USA	Survey followed by an interview with healthcare professionals	Cancer	233 healthcare professionals and 248 PRO researchers	Explore interpretation accuracy and clarity ratings of graphical formats and difference score representations.	Participants were accurate in their interpretation of PRO line graphs when the directionality of the score was indicated with a label “better”. Participants were more accurate in their interpretation of pie charts compared with bar graphs, for the display of proportions.	Q1 Q2	Level 3	Very High
Edbrooke-Childs et al, ³² 2016, UK	Pre-post observational study	Child mental Health	48 healthcare professionals attended the 1-day training course, 17 healthcare professionals attended the 3-day training course	Evaluate the effect of the training courses on attitudes and self-efficacy towards PROMs and feedback.	Increased time and duration of PROMS training showed greater improvement in attitudes towards PROMS, feedback attitudes and PROM self-efficacy.	Q1 Q3	Level 3	Moderate
Forsberg et al, 2015, ²⁶ USA & Sweden	Case study	Pain and spin conditions, rheumatology, and private healthcare	3 case studies of PRO feedback used in routine practice	Describe the principles and lessons learned from using PROs in the 3 case studies.	Healthcare professionals need to be able to place the PRO results within the context of the patient’s current clinical state, prognosis, and attitudes (e.g. a patient’s health status may be declining despite receiving best care). Healthcare professionals need to know what to do with the results, such as when the results are suggesting a significant health problem.	Q3	Level 4	High

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Hartzler et al, ³³ 2016, USA	Preliminary focus groups and interviews, followed by a pre-post study	Prostate cancer	The focus group included 60 prostate cancer survivors. 50 patients and 50 providers completed the interviews. 12 patients completed the pre-post observation	The focus groups assessed the needs of patients in relation to PROM feedback. The interviews evaluated preferred feedback methods. The pre-post study evaluated self-efficacy, satisfaction, communication, and compliance with the PRO dashboard.	Patients prioritized needs for dashboards to compare longitudinal trends and provide comparative groups. Patients and providers preferred bar charts and line graphs compared with tables and pictographs.	Q1 Q2	Level 2	Low
Hildon et al, ³⁴ 2012, UK	Focus groups	Knee surgery	45 patients who were planning or had undergone knee surgery	Thematic analysis of patients preferred PROM format.	Patients were generally positive about the use of bar charts and caterpillar plots. Opinions were mixed for tables and tables with icons. Patients did not like funnel plots. Patients liked the use of 'traffic-light' colours scheme and did not like the use of confidence intervals.	Q1 Q2	Level 4	High

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB I Level of Evidence	Strength of Evidence
Jensen et al, ²⁸ 2016, USA	Workshop proceedings	All healthcare areas	519 participants (including patients, healthcare professionals, researchers, healthcare system leaders and policy makers) attended the workshop, either in-person or online	Summary of workshop outcomes	Healthcare professionals should be provided with guidance in interpreting PRO scores, as they may not know the meaning of just raw scores. Translate PROs into specific actions for healthcare professionals by establishing clear recommendations on how to respond to PRO scores in clinical settings.	Q3	Level 5	High
Kuijpers et al, ³⁵ 2016, UK, Netherlands, Austria & Poland	Questionnaire	Cancer	548 patients with cancer and 227 healthcare professionals (doctors and nurses)	Understanding of PROM scores and preferences for different formats	Patients had no preference between non-colours bar charts and non-coloured line graphs. Patients preferred coloured bar charts over coloured line graphs. Healthcare professionals showed a preference for line graphs with ‘traffic-light’ coloured thresholds. Understanding did not differ between graphical formats for patients or healthcare professionals.	Q1 Q2	Level 4	High
Oliver et al, ²⁷ 2019, Australia, USA & Sweden	Case study	Multiple sclerosis, spinal care, and rheumatology	3 case studies of PRO feedback used in routine practice	Features that aid in the interpretation of PROs in the 3 case studies	The use of colour coding and threshold indicators, linked decision support functions (such as predictive calculators) can aid interpretation of PRO scores.	Q1	Level 4	Very low

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Snyder et al, ¹¹ 2019, USA	Consensus panel	Cancer	Participants included healthcare professionals, PRO researchers, patients and caregivers. 28 participants in meeting 1, and 27 participants in meeting 2 (participants were not mutually exclusive)	A modified Delphi process to develop recommendations for PRO data display.	Recommendations for the display of PRO data include using labelling and thresholds, not mixing score direction in a single display, accommodating both normed and non-normed scoring, displaying confidence intervals, indicating possibly concerning results.	Q1 Q2	Level 5	High
Tabil et al, ³⁶ 2018, USA	Interview	Primary care	23 patients in primary care	Thematic analysis of the patient's perception of the utility of PRO in primary care.	The patients found the colour coding severe symptoms useful but recommended the addition of 'traffic-light' colour scheme.	Q1	Level 4	High
van Overveld et al, ³⁷ 2017, Netherlands	Semi-structured interview	Head and Neck	37 patients, healthcare professionals (doctors, nurses, speech pathologist, dietician, allied health), and health insurers.	Content analysis of participants preferred PRO feedback method.	Patients want PRO feedback to include explanations of how to read the PRO graph, the inclusion of a comparison, and the feedback delivered around once a year. Healthcare professionals want PRO feedback to be simple and include a comparison groups (such as national average, best and worst performer). Healthcare professionals want PRO feedback between 1-4 times a year and receive the feedback via email.	Q1 Q2 Q3	Level 4	High

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JBIC Level of Evidence	Strength of Evidence
Wu et al, ³⁸ 2016, USA	Semi-structured interview	Cancer	42 cancer patients and 12 healthcare professionals (doctors and nurses)	Evaluate participants views of a webtool that was designed to allow PRO use in clinical practice.	Patients and healthcare professionals recommended having PRO score directionality be consistent, and more explanation of the score meaning. Healthcare professionals also recommended including if the score indicates better or worse health.	Q1	Level 4	High

Note. JBI = Joanna Briggs Institute. PRO = Patient reported outcome. PROM = Patient reported outcome measure. USA = United States of America. UK = United Kingdom.

Table 2. Characteristics of the included grey literature

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Aaronson et al. User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice. Version 2: January 2015. ⁵⁴	http://www.isoqol.org/UserFiles/2015UsersGuide-Version2.pdf	User's guide	09 July 2019	<p>A User's Guide developed by a team from the International Society for Quality of Life Research to provide practical guidance for clinicians with an interest in using PRO data in clinical practice. A combination of different tools to facilitate PRO data interpretation were recommended, and their advantages and disadvantages were described. Recommended (e.g. tools to aid PRO data interpretation vary depending on whether the patient's current score or a change in score is fed back).</p> <ul style="list-style-type: none"> Barriers: a lack of familiarity with PRO data among clinicians, time and resource constraints, fitting the use of PRO data within existing clinical workflows. Enablers: the provision of simple written guidance of PRO scoring meaning (e.g. higher scores mean better functioning) can provide a general indication of the meaning of scores, but will not provide information about the clinical importance of results.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Batalden et al. Enabling uptake of a registry-supported care and learning system in the United States: A report to the Robert Wood Johnson Foundation from Karolinska Institutet and The Dartmouth Institute, 2014. ⁴⁴	http://srq.nu/wp-content/uploads/2014/10/Summary-Report-4-30-14-FINAL.pdf	Technical report	10 July 2019	<p>The authors outlined a synergistic, learning health system model based on a case study from the Swedish Rheumatology Quality (SRQ) Registry whereby several data feedback systems were involved. PRO data were fed forward in a shared information environment and combined with clinical data displayed on a dashboard for outcome evaluation and clinical decision-making</p> <ul style="list-style-type: none">Barriers: a lack of interoperability between health information systems coupled with administrative workloads for clinicians, time and resource constraints in clinical practice.Enablers: creating seamless exchange of PRO data across health information platforms, the creation of PROs terminology and data exchange standards to facilitate point-of-care data solutions.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Canadian Institute for Health Information (CIHI). Health outcomes of care: An idea whose time has come, 2012. ¹	https://secure.cihi.ca/free_products/HealthOutcomes2012_EN.pdf	Technical report	23 July 2019	<p>A report produced by authors from Statistics Canada and the Canadian Institute for Health Information which presented PRO data developments options (using several case studies) to address gaps related to health outcomes. The authors included information related to challenges involved with the use of PROs among healthcare professionals.</p> <ul style="list-style-type: none"> Barriers: concerns related to the need for additional time and resources to facilitate uptake of PROs among clinicians. Enablers: engagement of clinicians, the implementation of incentives to encourage use of PRO data, and the need for further research related to casemix adjustment methods for PRO data.
Canadian Institute for Health Information (CIHI). PROMs Background Document, 2015. ⁴⁷	https://www.cihi.ca/sites/default/files/document/proms_background_may21_en-web.pdf	Report	23 July 2019	<p>The authors provided an overview of the coordinated approach to PROMs collection and reporting established in Canada, including the initial implementation steps and a review of the international PROMs landscape.</p> <ul style="list-style-type: none"> Barriers: a lack of collection of risk adjustment variables and data linkage processes for PRO data. Enablers: implementation of a coordinated, timely reporting approach and the ability to produce comparable PRO data report formats (across jurisdictions) to drive system improvements.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Canadian Institute for Health Information (CIHI). CIHI PROMs Forum Proceedings, 2015. ⁵³	https://www.cihi.ca/sites/default/files/document/proms_forum_proceedings_-_may_26_enweb.pdf	Forum Proceedings	23 July 2019	<p>An outline of the proceedings from a PROMs Forum hosted by the Canadian Institute for Health Information. In brief, the value of targeting PROs data initiatives towards clinicians was outlined, including three clinical areas (e.g. renal care) in which well-established PROs reporting mechanisms were determined to be most desirable.</p> <ul style="list-style-type: none">Barriers: a lack of timeliness for PRO data reporting, data capture delays, reporting biases, and a lack of establishment of PRO outcome thresholds/performance targets were identified as a challenge for engaging clinicians.Enablers: leveraging existing infrastructure to facilitate collection and reporting of PROs data and the engagement of clinical champions which were identified as success factors for PROMs initiatives.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Canadian Institute for Health Information (CIHI). Patient-centred measurement and reporting in Canada launching the discussion toward a future state, 2017. ⁴⁵	https://www.cihi.ca/sites/default/files/document/visioning-day-paper-en-web.pdf	Technical report	26 July 2019	<p>The authors presented a summary report based on presentations delivered at an invitational visioning day hosted by the Canadian Institute for Health Information. In brief, a common set of priorities for measurement and reporting of PRO data were highlighted among 33 participants.</p> <ul style="list-style-type: none"> Barriers: a lack of cross-country coordination of PRO data initiatives and limited capacity for clinicians/services/systems to compare results internationally. Enablers: provision of PRO data education, guidelines and work tools targeted towards clinicians to help with the interpretation of routinely reported PRO results and to understand how to improve care delivery.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Cappelleri et al. Patient-Reported Outcomes: Measurement, Implementation and Interpretation, 2014 ⁵⁰ .	https://www.crcpress.com/Patient-Reported-Outcomes-Measurement-Implementation-and-Interpretation/Cappelleri-Zou-Bushmakina-Alvir-Alemayehu-Symonds/p/book/9781138199590	Book/Book chapter	17 July 2019	<p>The authors provided a comprehensive overview of various PRO data elements (e.g. measurement validity/reliability, missing data and statistical techniques) that can be used to advance the validation and use of these data.</p> <ul style="list-style-type: none">Barriers: issues associated with missing data and response-shift bias were highlighted for PRO datasets. The authors suggested the use of a statistical analysis plan to ensure analyses/reports are insensitive to missing data.Enablers: electronic data capture to minimise missing PRO data, the use of descriptive statistics for presenting PRO scores, exploring the distribution of PRO datasets as an essential elements of data summarization.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Chen J. Integrated Care: Patient reported outcome measures and patient reported experience measures - A rapid scoping review, 2015. ⁴²	https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0009/281979/ACI_Proms_Premis_Report.pdf	Technical report	08 July 2019	<p>A report based on the outcomes of a scoping review that was undertaken to examine the issues of implementing a large-scale PROMs initiative, with a particular focus on patient-centre care in New South Wales, Australia.</p> <ul style="list-style-type: none"> Barriers: issues related to the phenomenon of response shift for PRO data and a lack of established clinically meaningful cut-offs (e.g. particularly for longitudinal data). The author included several analytical methods that can be used to identify these issues. Enablers: stakeholder engagement and generating clinical 'buy-in' may enable uptake and use of PRO data if clinicians are educated and trained to understand the relevance of these data and their use for quality improvement purposes.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Clinical Oncology Society of Australia (COSA). Implementing monitoring of patient-reported outcomes into cancer care in Australia - A COSA Think Tank Report, 2018. ⁴¹	https://www.cosa.org.au/media/332504/cosa_pros_think_tank_report_final.pdf	Technical report	12 July 2019	<p>A report based on the findings from a Think Tank that involved 32 participants and was focussed on approaches to embed PRO assessment as part of routine cancer care in Australia. The authors highlighted effective methods for implementing PRO monitoring and discussed the benefits of using PRO data in clinical practice.</p> <ul style="list-style-type: none">Barriers: a lack of awareness of PROs and perceptions of risk among clinicians, system-level issues (e.g. limited resources, variability of information technology systems), the alteration of clinical workflows to facilitate use of PROs.Enablers: education and training for clinicians (e.g. why PRO data are important, how to use these data as part of clinical practice) and engaging clinical champions.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Desomer et al. Use of patient-reported outcome and experience measures in patient care and policy. Belgian Health Care Knowledge Centre, 2018. ⁴	https://kce.fgov.be/en/use-of-patient-reported-outcome-and-experience-measures-in-patient-care-and-policy	Technical Report	26 July 2019	<p>A report based on an evaluation of the uses, benefits, barriers and facilitators of patient-reported outcome and experience measures in clinical practice undertaken by a research team from the Belgian Health Care Knowledge Centre (KCE). The authors included an analysis of international initiatives and a review of the peer-reviewed literature along with a set of recommendations to facilitate the introduction of PROs.</p> <ul style="list-style-type: none"> Barriers: PRO data selection bias (e.g. due to cultural or language barriers), lack of interoperability between information technology systems, data reporting time delays, a lack of knowledge about the value of PROs and perceived administrative burden among clinicians. Enablers: using a bottom-up (clinically driven) approach combined with top-down guidance (policy driven) to improve use of PROs in clinical practice, accessible data infrastructure (e.g. interactive tools for analyses and data visualization) and easy to read reports linked to concrete actions for clinicians.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Duckett et al. Targeting zero: Supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care - report of the Review of Hospital Safety and Quality Assurance in Victoria, 2016. ⁴⁰	https://www.dhhs.vic.gov.au/sites/default/files/documents/201610/Hospital%20Safety%20and%20Quality%20Assurance%20in%20Victoria.pdf	Technical Report	26 July 2019	<p>A report based on a review of the governance of quality and safety monitoring and data reporting throughout hospitals located in Victoria, Australia. The review process included stakeholder and expert consultation methods and the authors presented several recommendations, including the establishment of systematic collection of patient-reported outcome measures at a state-level.</p> <ul style="list-style-type: none">N/A: information related to barriers and enablers for PRO data was not included.
Duckett et al. Strengthening Safety Statistics: How to make hospital safety data more useful: The Grattan Institute, 2017. ⁴⁹	https://grattan.edu.au/wp-content/uploads/2017/11/893-strengthening-safety-statistics.pdf	Technical Report	26 July 2019	<p>A technical report focussed on methods to use to enhance the presentation of hospital safety data (in general), which also included information related to PRO data. The author suggested that aggregated data must be presented in a meaningful and simple ways and directed towards appropriate audiences who can take action.</p> <ul style="list-style-type: none">Barriers: the inclusion of statistical information and the assumption that clinicians will confidently interpret data without an adequate explanation or tailored training.Enablers: the identification of the audiences' needs and preferences and use of visual aids (e.g. line or bar graphs) were recommended for data reporting purposes to reduce information overload and increase the utility of the data.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Franklin et al. Framework to guide the collection and use of Patient- Reported Outcome Measures in the learning healthcare system, 2017. ⁴³	https://egems.academyhealth.org/articles/10.5334/egems.227/	Technical report	09 July 2019	<p>A report outlining the findings based on key informant interviews (conducted with 46 individuals who were actively engaged in the use of PROMs in diverse clinical settings), two interactive web-based discussions and an in-person workshop. The authors presented an implementation framework and included a toolkit of strategies to accelerate collection and use of PROMs.</p> <ul style="list-style-type: none"> Barriers: altered clinical workflows; limited web-based tools to support real-time scoring and trending of data across clinical settings, lack of data visualization tools. Enablers: the establishment and availability of population norms and benchmarks for PRO measures to compare data within and between specific clinical groups were outlined as enablers for use among clinicians, quality leaders and health system payers.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Nelson et al. Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case studies from Dartmouth, Karolinska and Group Health. Lebanon, New Hampshire: The Dartmouth Institute for Health Policy and Clinical Practice, 2012. ³⁹	https://www.researchgate.net/publication/232607583_Using_Patient-Reported_Information_to_Improve_Health_Outcomes_and_Health_Care_Value_Case_studies_from_Dartmouth_Karolinska_and_Group_Health	Technical report	11 July 2019	<p>A peer-reviewed, technical report outlining the feasibility, utility and lessons related to PROs data collection systems. The authors presented three case studies from PROs initiatives based at the Dartmouth-Hitchcock Spine (Lebanon), the Swedish Rheumatoid Arthritis Registry and Group Health Cooperative (Seattle, Washington).</p> <ul style="list-style-type: none">Barriers: the need for high adoption, completion and follow-up rates for PRO data, some clinicians may not know what to do with the results and decision support resources (e.g. clinical practice guidelines) need to be developed to guide responses to PROs results.Enablers: leveraging PROs by supplementing these data with other information sources (e.g. diagnosis data, biometrics), the use of standardized training materials for clinicians and co-designing data displays with end-users to promote utility of PROs among clinicians.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
NSW Agency for Clinical Innovation. Patient Reported Measures – Program overview, 2018. ⁴⁶	https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0004/415219/ACI18050_PRM_ProgOverview_Guide_v1.pdf	Program overview and guide	05 July 2019	<p>A guide and overview of the Agency for Clinical Innovation Patient Reported Outcome Measures program established in New South Wales, Australia. The document outlined implementation considerations related to PROs.</p> <ul style="list-style-type: none"> Barriers: PRO data collection and use may be duplicative or burdensome for clinicians, there may be a perceived lack of relevancy or meaning to clinicians, response rate issues. Enablers: routine reporting of PRO data back to clinicians to encourage them to take action. (e.g. with the ability to view data in real time and perform analytics of patient populations).

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Paxton Partners, Patient-Reported Outcome Measures: Literature scan, personal communication, 2018.	N/A	Report	14 June 2019	<p>A report based on the implementation considerations required for the establishment of a PROMs collection system in Victoria, Australia. The authors included a review of the literature and evidence from the experiences of early PRO data adopters located in other countries and jurisdictions.</p> <ul style="list-style-type: none">Barriers: variations in the approaches used to collect PRO data (e.g. the PRO measure used, the patient population, format and timing of feedback and the level of aggregation of the data), resources and costs required.Enablers: clinician engagement and the collection of PRO data via integration with existing data collection systems (e.g. clinical quality registries) to allow these data to be fed back and used at the micro-, meso- and macro-level.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Peterson A. Learning and understanding for quality improvement under different conditions - An analysis of quality registry-based collaboratives in acute and chronic care, 2015. ⁵²	http://hj.diva-portal.org/smash/get/diva2:871675/FULLTEXT01.pdf	Dissertation	08 July 2019	<p>A dissertation based on the use of Quality Improvement Collaboratives (QICs) in three national registries (which are also used for follow-up purposes) in Sweden. The author used an interactive approach to examine if, and how, QICs contributed to quality improvement in the provision of healthcare.</p> <ul style="list-style-type: none"> Barriers: issues related to missing or incomplete data in healthcare, lack of motivation among clinical teams, time constraints, staff turnover in clinical settings, clinicians need to know how to extract data from different systems. Enablers: continuous monitoring of a clinical teams' own data (in general) and ability to retrieve data in real time, learning from others and the formation of 'Communities of Practice' during quality improvement initiatives.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Raine et al. Patient-reported outcome measures and the evaluation of services. Challenges, solutions and future directions in the evaluation of service innovations in health care and public health: National Institute for Health Research, 2016. ⁵¹	https://www.ncbi.nlm.nih.gov/books/NBK361255/	Book/Book chapter	16 July 2019	<p>The authors provided an overview of the progress made in relation to PROs and outlined the main challenges that need to be addressed to further the field. Using the experiences and lessons learnt from several large-scale PROMs programs in different countries, the authors describe the role of PRO data and the need to engage clinicians to ensure uptake.</p> <ul style="list-style-type: none">Barriers: a lack of high-level evidence in the field of PROMs, a lack of integration of PRO data within health records and existing processes of care, missing or incomplete data (e.g. for sensitive questions), score interpretation difficulties and response shift bias.Enablers: the establishment of essential training and education mechanisms for clinicians to strengthen their understanding of PRO data and interpretation of results.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Snyder et al. Testing Ways to Display Patient-Reported Outcomes Data for Patients and Clinicians, 2018. ⁵⁵	https://www.pcori.org/sites/default/files/Snyder054-Final-Research-Report.pdf	Research Report	26 July 2019	<p>A final research report produced by a research team from the Patient-Centred Outcomes Research Institute (PCORI) in the United States. Using a three-part mixed methods study, the authors identified and tested a range of approaches for presenting PRO data (individual- and group-level) to promote understanding among clinicians and patients from cancer treatment settings.</p> <ul style="list-style-type: none"> Barriers: a lack of information is available to explain the methods used to determine clinical importance for PRO data, a lack of standardization related to scoring of PRO data and how these data are presented for use in clinical practice. Enablers: the provision of guidelines, work tools and education/training targeted towards different audiences to assist with PRO data interpretation.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Thompson et al. Patient-reported Outcome Measures: An environmental scan of the Australian healthcare sector, 2016. ³	https://www.safetyandquality.gov.au/sites/default/files/migrated/PROMs-Environmental-Scan-December-2016.pdf	Final report (environmental scan)	14 June 2019	<p>A report based on an environmental scan of the literature undertaken by authors from the Australian Health Services Research Institute. The authors described status of the collection and use of PROMs initiatives in the Australian healthcare system.</p> <ul style="list-style-type: none">Barriers: a limited number of empirical examples of the application of aggregated PRO data for benchmarking purposes were found, patterns and case studies for PRO data collection were found to be variable.Enablers: the provision of timely reports, facilitation of benchmarking workshops for clinicians, a high level of clinician engagement and a willingness to integrate PROs within existing data collection systems.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Williams et al. Patient-reported outcome measures: Literature review, 2016. ⁵	https://www.safetyandquality.gov.au/sites/default/files/migrated/PROMs-Literature-Review-December-2016.pdf	Final report (literature review)	14 June 2019	<p>A report based on the findings from a literature review conducted by researchers from the Australian Health Services Research Institute. The authors describe the international evidence to support the rationale for PROs data collections and different mechanisms used to facilitate collection, data uses and the impact of these data.</p> <ul style="list-style-type: none"> Barriers: the resources/costs required for PRO data collection, response burden/patient confidentiality concerns (e.g. sensitive questions), and time and workload constraints for clinicians to implement PROs into routine practice. Enablers: the use of integrated information technologies to support electronic capture of PRO data and real-time feedback to clinicians, training and support for clinicians to effectively use PRO data (e.g. increased familiarity with measures and interpretation of results).

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
World Economic Forum. Value in healthcare laying the foundation for health system transformation. Cologny/Geneva, Switzerland: World Economic Forum, 2017. ⁴⁸	http://www3.weforum.org/docs/WEF_Insight_Report_Value_Healthcare_Laying_Foundation.pdf	Report	05 July 2019	<p>A report based on a collaborative project undertaken by authors from the World Economic Forum and The Boston Consulting Group whereby the foundational principles of value-based health care, including information related to PRO data were described.</p> <ul style="list-style-type: none">Barriers: there is a lack of development of enhanced benchmarking methodologies for data (e.g. data collected through the use of clinical quality registry infrastructure).Enablers: interoperability issues and semantic interoperability issues related to linking data (in general) and for performing risk-adjustments to draw meaningful inferences from data (i.e. which can also be extended to PRO data).

Note. PRO: Patient-reported outcome. PROM: Patient-reported outcome measure.

Table 3. Summary of different PRO data presentation formats.

Graphical Format	Summary	Healthcare professional preference
Tables with numerical data	Presentation of data in tables is considered more neutral and needing less explanation for interpreting the meaning of the data than when presented in graphs. Tables with large amounts of data may be perceived as cluttered and lacking visual clarity, making them difficult to read. ^{31 34}	+/- Mixed
Use of icons/pictographs	Most healthcare professionals find tables with icons to be insufficient and lacking transparency. ^{31 33} This is the inverse to patients, who prefer such displays due to their simplicity. ³⁴	- Negative
Line graphs	Line graphs are the preferred approach for presenting individual patient PRO scores over time. ^{6 11 24 33 35 55} However, if there are too many outcome variables, the line graph may become difficult to interpret. ³⁷ The recommended maximum number of lines that should be displayed within a single graph is four. ²⁴	+ Positive
Bar graph	Bar graphs are widely liked as they are clear and facilitate comparison. ^{24 33} They can also easily include additional information (e.g. confidence intervals and descriptive labels). The use of confidence intervals should be accompanied by a written explanation to facilitate interpretation of the data. ³¹ To reduce confusion, the recommended maximum number of bars within a single graph should be six. ²⁴	+ Positive
Funnel plots	Funnel plots can provide a good overview, but also contain a lot of information. Those unfamiliar with funnel plots may find them confusing. ^{31 34 37} As such, the use of funnel plots should be accompanied by a detailed explanation of how to be interpreted.	+/- Mixed
Caterpillar plots	Caterpillar plots are less familiar to healthcare professionals and patients than bar graphs. ^{31 34} Though caterpillar plots are clearer than bar graphs containing confidence intervals, and can facilitate rapid comparisons between larger amounts of groups. ^{31 37}	+ Positive
Spider plots or radar chart	Healthcare professionals who are unfamiliar with spider plots may find them confusing and lacking clarity. ³¹ Spider plots also make displaying additional information such as confidence intervals or statistical significance difficult. ³¹	- Negative
Pie Charts and Stacked Bar Graphs	Pie charts and stacked bar graphs are both reasonable formats for presenting proportions visually, especially when there are big differences. ^{11 37} Healthcare professionals are more accurate at interpreting stacked bar graphs compared with pie charts, ³⁷ while patients can interpret pie charts more accurately. ²	+ Positive

Box 1. Summary of basic guiding principles

Recommendations to guide best practice in PRO data feedback to clinicians:

- Reporting PRO data back to clinicians should be done in a simple format that is easy to read to reduce the chance of misinterpretation.²⁵
- Features that may be used to facilitate simple reporting include: reducing the number of metrics presented within a report and minimising page counts.²⁹
- PRO reporting should avoid mixing the directions of scores that are displayed. Exceptionally clear labelling, titling and annotations should also be used to increase interpretability.^{2 11 35}
- The use of coloured arrows (e.g. green for better scores and red for worse scores) may enhance clinicians’ interpretation of PRO scores presented across different domains.³⁵
- Clinically significant differences and confidence intervals should be included where possible. There is a move away from reporting just the *p*-value.^{6 11}

Recommendations for optimal data presentation formats:

- The choice of which graphical format to use to display the PRO data, will depend on the type of data (i.e. single outcome/multiple outcomes, single time point/multiple time points, amount of data to display etc.) and the intended purpose of the data.²⁴
- Line graphs and bar graphs are preferred and reduce the chance of misinterpreting the data.^{24 33}
- The maximum number of bars presented within a bar graph should be 6, while the maximum number of lines within a line graph should be 4.²⁴
- More complex displays such as funnel plots or caterpillar plots should be accompanied by a description of how to interpret the graph.³¹

Recommendations to address barriers and enablers associated with feedback and reporting of PROs:

- The inclusion of clinical/local champions is critical to generate buy-in from the clinical community (Aspex Consulting, Evaluation Framework and Initial Appraisal of PROMS: Final Report, personal communications, 2018).
- PROs should be reported in a way that can be directly translated into specific actions to guide clinicians to respond to concerning results.^{26 28}
- Training and education are needed to improve the clinician’s ability to interpret PRO data, to integrate the use of PROs into their routine practice, and to respond to concerning results.^{39 51}
- The optimal time intervals for PRO feedback needs to be determined. One suggested timeframe for audit and feedback to clinicians is 1 to 4 times a year.³⁷

Legend: Figure 1 shows the study identification and selection process that was applied to the academic literature during the study. The original database search resulted in 4445 records identified. An additional 4 records were identified from other sources. After duplicates were removed, there were 3480 unique records. The title and abstract screening process excluded 3191 records for being unrelated to the topic. The remaining 289 records underwent the full-text screening process, where 270 records were excluded for the following reasons: 31 were not about patient reported outcomes, 159 did not feed back the patient reported outcomes, 21 were the wrong article type, 11 were the wrong article setting, and 2 records were not in English. 19 unique records were included in the final synthesis.

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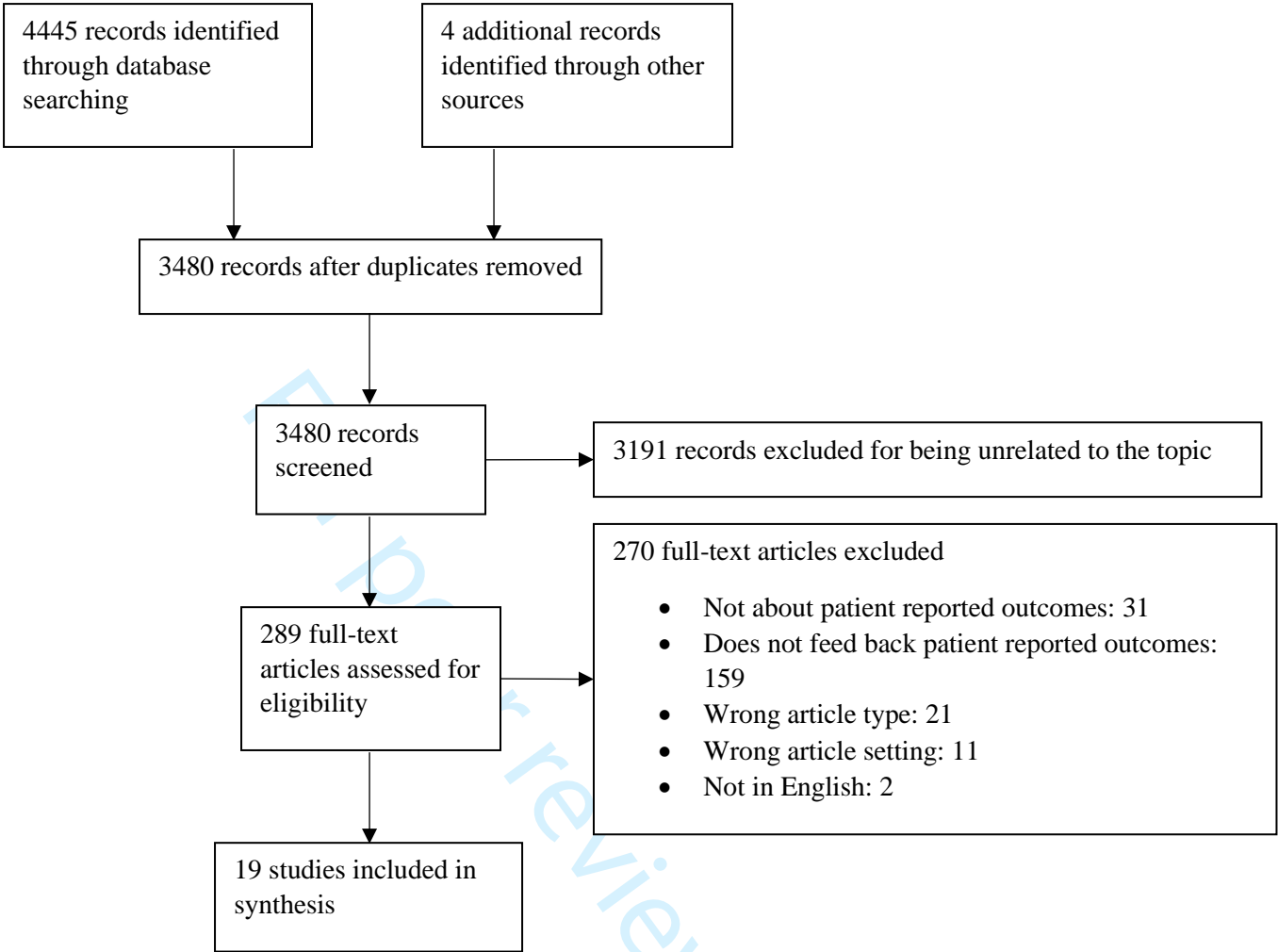


Figure 1. PRISMA flow chart illustrating findings from the academic literature search²³

Appendix 1. Data extraction tool used for academic literature

	Description
Author	
Year	
Title	
Country	
Type of Article	
Characteristics of patient	
Characteristic of professional	
Clinical area of practice	
Characteristic of study	
Number of participants (included, excluded, partially followed up and lost)	
Unit of analysis	
Level of feedback (individual [micro]/group-level [meso]/population level [macro])	
Feedback for patient/clinician	
Type of PRO(M) used	
Purpose of feedback (influence patient relations, change clinical practice etc)	
Findings related to existing evidence on best practice in the readability and feedback of PRO data to healthcare professionals	
Findings related to what PRO data presentation formats were used	
Findings related to factors that influence PRO data interpretation or use in clinical practice	
Additional notes	

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Appendix 2. Data extraction tool used for the grey literature

	Description
Author/Organization	
Year of publication	
Title	
Country	
Type of document	
Date of access	
URL	
Background Patient Reported Outcome Measures information	
Patient Reported Outcomes data display features	
Patient Reported Outcomes data feedback mechanism(s)	
Identified barriers to Patient Reported Outcomes data uptake among clinicians	
Identified enablers to Patient Reported Outcomes data uptake among clinicians	
Patient Reported Outcomes data issues (e.g. statistical/analytical methods)	
Additional notes	

Supplemental Table 1. Breakdown of academic literature search strategy and key words.

Database	Search string	Results
Embase	Patient-reported outcome measures Patient reported outcomes PROMs PROM PROs PRO 1 or 2 or 3 or 4 or 5 or 6 – 213251 results Patient-centered care Patient centred care Health care policy Value based health care Low value care Quality of care Health care quality Quality improvement 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15– 112842 results Feedback Audit Review Benchmark Practice data Hospital* data Dashboard Dash board Public* report* 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 – 7 and 16 and 26 - Limit 27 to (English language and yr="2009-Current")	905
Ovid Medline	1. Patient-reported outcome measures 2. Patient reported outcomes 3. PROMs 4. PROM 5. PROs 6. PRO 7. 1 or 2 or 3 or 4 or 5 or 6 – 213251 results 8. Patient-centered care 9. Patient centred care 10. Health care policy 11. Value based health care 12. Low value care 13. Quality of care 14. Health care quality 15. Quality improvement 16. 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15– 112842 results 17. Feedback 18. Audit	390

	19. Review 20. Benchmark 21. Practice data 22. Hospital* data 23. Dashboard 24. Dash board 25. Public* report* 26. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 – 27. 7 and 16 and 26 – Limit 27 to (English language and yr="2009-Current")	
Scopus	TITLE-ABS-KEY ("Patient reported outcome measures" OR "patient reported outcomes" OR "PROMs" OR "PROM" OR "PROs" OR "PRO") AND ("patient centered care" OR "patient centred care" OR "health care policy" OR "value based health care" OR "low value care" OR "quality of care" OR "health care quality" OR "quality improvement") AND ("feedback" OR "audit" OR "review" OR "benchmark" OR "practice data" OR "hospital* data" OR "dashboard" OR "dash board" OR "public* report") AND (LIMIT-TO (DOCTYPE , "ar") OR LIMIT-TO (DOCTYPE , "re") OR LIMIT-TO (DOCTYPE , "ed") OR LIMIT-TO (DOCTYPE , "cp")) AND (LIMIT-TO (SUBJAREA , "MEDI") OR LIMIT-TO (SUBJAREA , "HEAL")) AND (LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009)) AND (LIMIT-TO (LANGUAGE , "English"))	2896
Web of science	TOPIC: (("patient reported outcome measures" OR "patient reported outcomes" OR "PROMs" OR "PROM" OR "PROs" OR "PRO") AND ("patient centered care" OR "patient centred care" OR "health care policy" OR "value based health care" OR "low value care" OR "quality of care" OR "health care quality" OR "quality improvement") AND ("feedback" OR "audit" OR "review" OR "benchmark" OR "practice data" OR "hospital* data" OR "dashboard" OR "dash board" OR "public* report*")) Timespan: 2009-2019	220

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3-4
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	4
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	4
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	4,5
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	4,6
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplementary table
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	5
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	5,6,7
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	5,6
Critical appraisal of individual	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe	6

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
sources of evidence§		the methods used and how this information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	7
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	7, Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Table 1
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Table 1
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Table 1
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Table 1, 8-14
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Box 1, 14-16
Limitations	20	Discuss the limitations of the scoping review process.	16
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	17
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	2

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.
 * Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.
 † A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).
 ‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.
 § The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*. 2018;169:467–473. doi: 10.7326/M18-0850.

BMJ Open

Feedback of Patient Reported Outcomes to healthcare professionals for comparing health service performance: A scoping review

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Primary Subject Heading:	Public health
Secondary Subject Heading:	Patient-centred medicine, Communication
Keywords:	Clinical audit < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PUBLIC HEALTH, AUDIT, HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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Feedback of Patient Reported Outcomes to healthcare professionals for comparing health service performance: A scoping review.

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Feedback of Patient Reported Outcomes to healthcare professionals for comparing health service performance: A scoping review.

Abstract

Objective: Patient reported outcomes (PROs) provide self-reported patient assessments of their quality of life, daily functioning, and symptom severity after experiencing an illness and having contact with the health system. Feeding back summarised PRO data, aggregated at the health-service level, to healthcare professionals may inform clinical practice and quality improvement efforts. However, little is known about the best methods for providing these summarised data in a way that is meaningful for this audience. Therefore, the aim of this scoping review was to summarise the emerging approaches to PROs ‘service-level’ feedback to healthcare professionals.

Setting: Healthcare professionals receiving patient reported outcome data feedback at the health-service level.

Data sources: Databases selected for the search were Embase, Ovid Medline, Scopus, Web of Science, and targeted web-searching. The main search terms included: ‘patient-reported outcome measures’, ‘patient-reported outcomes’, ‘patient-centred care’, ‘value-based care’, ‘quality improvement’ and ‘feedback’. Studies included were those that were published in English between January 2009 and June 2019.

Primary and secondary outcome measures: Data were extracted on the feedback methods of PROs to patients or healthcare providers. A standardised template was used to extract information from included documents and academic publications. Risk of bias was assessed using Joanna Briggs Institute Levels of Evidence for Effectiveness.

Results: Overall, 3480 articles were identified after de-duplication. Of these, 19 academic publications and 22 documents from the grey literature were included in the final review. Guiding principles for data display methods and graphical formats were identified. Seven

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major factors that may influence PRO data interpretation and use by healthcare professionals were also identified.

Conclusion: While a single best format or approach to feedback PRO data to healthcare professionals was not identified, numerous guiding principles emerged to inform the field.

Strengths and limitations of this study

- This scoping review provides a novel summation of the published and grey literature of the guiding principles for effectively feeding back Patient Reported Outcome data to healthcare providers.
- The search strategy was broad, including individual patient level, health-service level, and system level reporting of Patient Reported Outcome data to ensure no relevant articles were missed.
- The grey literature search was restricted to seven countries due to the limited timeframe for completing the study.
- Two reviewers conducted the literature syntheses, with one person completing the academic synthesis and one person completing the grey synthesis.
- Using a standardised data extraction process for both types of literature, the findings from this review inform the rapidly growing fields of improvement science and implementation research related to health-service level reporting of aggregate Patient Reported Outcome data to healthcare professionals.

INTRODUCTION

There is growing interest in the use of Patient Reported Outcomes (PROs) for all aspects of health care. This is because information available from administrative and routinely collected clinical data do not provide a comprehensive picture related to health outcomes once patients leave hospital.¹ PROs are outcome data collected directly from patients about their health and the potential impacts of treatments or management within the health system.² PROs are differentiated from Patient Reported Outcome Measures (PROMs), which are the instruments or survey tools used to obtain PROs.³ Reporting of PRO data can occur at the individual patient level and be used to inform decisions about patient-centred care, or at the aggregated service and system levels, and may be used to assess and compare organisational performance or for population surveillance.^{4 5}

PROs were originally developed for use in research, such as comparative effectiveness studies and clinical trials.^{6 7} However, the value of using PROs to inform clinical practice has since been realised.^{8 9} PROs have evolved in a somewhat disparate manner between different countries, with each country aligning the use of PRO collections with a slightly different emphasis.⁵ For example, in England the focus of PRO collections is on hospital performance in selected elective surgeries, whereas in the Netherlands and Sweden, collection of PROs predominately occurs through disease-specific Clinical Quality Registries (CQRs).⁵

Healthcare professionals have reported challenges in relation to interpreting the meaning and implications of PRO data.^{6 10} These challenges can arise due to the variation by which PRO data are used, scored, and reported.⁶ Methods for optimising the feedback of PRO data to healthcare professionals is an emerging field of research.^{2 11 12} Currently, little is known about the best methods for providing summarised PRO data in a way that is meaningful for health care providers. To the best of our knowledge, there is currently little

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empirical evidence available to support best practice in the feedback methods for PRO data, particularly at the health-service level.

The aim of this review was to investigate the emerging approaches to the feedback and report PRO data to healthcare professionals, in order to understand how to increase engagement and uptake of these data. Three questions were used to explore this aim: (1) What is the existing evidence on best practice in the readability and feedback of PRO data to healthcare professionals? (2) What PRO data presentation formats have the most utility for healthcare professionals? (3) Are there factors that influence PRO data interpretation or use in clinical practice?

METHODS

The rapid scoping review was undertaken by a research team with clinical expertise (nursing, allied health, psychology) from the Australian Stroke Clinical Registry (AuSCR) with over ten years’ experience collecting and reporting generic and disease specific PROs in consultation with end-users who work in hospitals or government¹³. Consultation was undertaken with government representatives from the Victorian Agency for Health Information including author MPK, who are collecting PROs data on an ongoing basis from health services, including hospitals. Weekly team meetings were held to ensure a standardised screening and data extraction process whereby information about papers under consideration were discussed based on the information gathered by author SH (Honours, Psychology) or OR (Honours, Health Information Management) using the relevant data extraction tool.

The methods used for the review (including inclusion criteria, search strategy, extraction and synthesis) were specified in advance in an unpublished protocol, based on the Joanna Briggs Institute Guidelines for conducting a scoping review.¹⁴ Two search strategies were used. The first covered the academic, peer reviewed literature and the second covered

grey literature (such as government reports and policy documents). Different strategies were used to search the two sources of evidence. Rapid review methods using recommended approaches by the Cochrane collaboration¹⁵ were drawn upon for this scoping review. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) was used for report results.¹⁶

Academic Literature Search

For the academic literature, four databases were selected , including: Embase; Ovid Medline; Scopus; and Web of Science. These databases were chosen to maximise the scope of articles that were retrieved. The search included phrases related to the following terms and concepts: patient-reported outcome measures, patient-reported outcomes, patient centred care, value-based care, quality improvement, feedback, audit, and dashboard. A full list of search terms and the combinations used is available in Supplemental Table 1.

Studies included were those that were published in English between January 2009 and June 2019, where the feedback methods of PROs to patients or healthcare providers were described. Studies prior to 2009 were excluded to accommodate a contemporary, timely and comprehensive summary. Abstract booklets, conference abstracts, and newsletters, were excluded. Publications for studies that were pilot/development/protocol projects, focused on testing a PRO measurement tool, or in which PROs were used as the endpoint outcome for an observational or comparative-effectiveness study were excluded. Further, studies related to primary care, emergency care or non-acute conditions (e.g. surgical interventions or interventional devices) were also excluded. The initial search was broad to include studies related to individual patient-level feedback of PRO data to ensure no relevant articles were missed, however, the synthesis of the literature focussed primarily on health-service level reporting of aggregate PRO data to healthcare professionals.

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All references identified from these searches were downloaded and imported into Covidence software.¹⁷ Following removal of duplicates, the screening process involved one reviewer (SH, Honours Psychology) reading the titles and abstracts of each article to determine relevance using the inclusion and exclusion criteria outlined above. The full text of the relevant articles was then assessed by one reviewer (SH), with a second reviewer (CW, Masters, Health Information Management) conducting an independent assessment on a subset of the articles to ensure standardisation. If any disagreements for study eligibility arose, these were resolved through discussion and consensus between the two reviewers. If disagreements were unable to be resolved using this approach, the article was to be reviewed by a third reviewer to determine eligibility. This latter process was not required. SK provided training for the team in conducting a review, as a past Cochrane reviewer. Additional support was provided by SK and DAC, who have extensive experience conducting literature reviews.¹⁸⁻²⁰

Academic Literature Data Extraction and Charting

Data from the included academic literature were systematically extracted using a predetermined data extraction template by one reviewer (SH). The extraction template was developed by the review team in consultation with VAHI representatives. The template was then piloted and adapted as necessary. The final extraction template included: characteristics of study participants (including age, profession, area of practice, and number of participants), type of article, which PROs were used, the purpose of the feedback, and the findings of the study. Findings were extracted from all included academic literature by selecting those text passages and outcomes that related to each research question. The academic data extraction tool is available in appendix 1.

Level of Evidence and Critical Appraisal of the Academic Literature

The methodological design of all included articles was assessed according to the Joanna Briggs Institute Levels of Evidence for Effectiveness²¹ by SH, in order to assess the

quality and rigour of the evidence. Studies were assigned Level 1 (experimental), Level 2 (quasi-experimental), Level 3 (analytical), Level 4 (descriptive) or Level 5 (expert opinion). Further, the included research articles were appraised for strength of evidence by one reviewer (SH) using the critical appraisal tools from the Joanna Briggs Institute.²² Each article was assigned a rating of quality based on how many of the criteria the article fulfilled (e.g. “Were the criteria for inclusion in the sample clearly defined?”). Studies that met all criteria were rated as very high, studies that met 80% or more of criteria were rated as high, studies that met 60% or more, 40% or more, and less than 40% of the criteria were rated as moderate, low, and very low respectively. While critical appraisal assessments are not mandatory for conducting a scoping review,¹⁴ given the breadth of studies and their designs that we were anticipating we felt that an assessment of the article quality was relevant to considering the evidence we were extracting.

Grey Literature Search

We elected to use similar methods to those of a previous PRO literature search conducted by Williams and colleagues (2016).⁵ The grey literature component of our search included Google searches, targeted website searches and snowballing of reference lists, where appropriate. The first ten pages of results retrieved from each Google search were reviewed.⁵ The following search terms were used:

- ‘Use of Patient-Reported Health Outcome Measures in (country)’
- ‘Feedback of Patient-Reported Health Outcome Measures in (country)’
- ‘patient-reported outcome measure + feedback + use in (country)’
- ‘Benchmarking of Patient-Reported Health Outcome Measures in (country)’

Due to the limited timeframe for completing the study, the grey literature search was restricted to seven countries. The countries included in the Google searches were Sweden, the

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Netherlands, Finland, Canada, United Kingdom, United States of America (USA) and Australia. The selection of these countries was based on the prior research of William and colleagues (2016)⁵ which found substantial examples of the use of PROs within these regions. The websites of relevant leading organisations (i.e. health agencies, government organisations, professional organisations, special interest groups, research institutes and universities) were also searched. For example, the websites of organisations such as: The Institute for Healthcare Improvement (IHI), The International Consortium for Health Outcomes Measurement (ICHOM) (i.e. the United States), The Dutch Institute for Clinical Auditing (DICA) (i.e. The Netherlands) and The Organisation for Economic Co-operation and Development (OECD) were searched. Further, the websites and Annual Reports of national clinical quality registries that were known to collect and report PRO data were also searched.

Similar to the inclusion criteria applied for the academic literature, materials that were published in English between 2009 and 2019 were included. Internet page entries without PROs data; focussed on single-centre studies or testing PRO instruments were excluded. We also excluded literature related to primary care, emergency care or surgical interventions/devices; did not relate to the target country; or were duplicate entries were excluded.

Grey Literature Data Extraction and Charting

A second data extraction template was used for the grey literature. Data from the included grey literature were systematically extracted using a predetermined data extraction template by two independent reviewers (OR, Honours, Health Information Management; and VM, Nursing). Similar to the methods used for the academic literature template, the grey literature data extraction template was developed by the review team in consultation with VAHI

representatives. The final template included information on: the type of document, title, name of the organisation that produced the document, background PROM information, PRO data display features, PRO data feedback mechanism(s) the identified barriers and enablers to PRO uptake among clinicians, and PRO data issues (e.g. statistical/analytical methods). The grey literature data extraction tool is available in appendix 2.

Collating and Synthesising Results

The data within the extraction forms used for the academic and grey literature templates were sorted according to which research question they contributed to answering. The findings were then grouped into themes (e.g. missing data, healthcare professional education and training) . Once established, each theme was presented and discussed between SH, OR and VM. The preferences of PRO data formats among healthcare professionals determined in the current study was summated from all articles that described PRO data formats preferences. An inductive approach was used to analyse the qualitative findings to address the research question related to factors that influence PRO data interpretation or use, whereby themes were developed by studying the findings and were considered how they fit within the developing themes.

Patient and Public Involvement

No patients were involved in setting the review questions or in the design of the initial protocol and overall study. No patients were asked to advise on the interpretation and write up of the results. This study forms the first component of a broader program of work initiated by VAHI and stakeholder engagement methods were used in the subsequent stages of the project.

RESULTS

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The initial search resulted in the identification of 4445 academic articles. Following the removal of duplicates 3480 unique articles remained, nineteen of which were included in the final review. Figure 1 summarises the academic literature search using a PRISMA flowchart.²³ The publication characteristics, level of evidence and quality appraisal of the included academic literature are available in Table 1. Research methods included two reviews,^{24 25} three case studies,^{12 26 27} two consensus panels,^{11 28} one opinion article,²⁹ and 11 observational studies.^{2 6 30-38} According to the Joanna Briggs Institute Levels of Evidence for Effectiveness,²¹ the nineteen included studies were classified according to the following levels: 1 (n=0), 2 (n=1), 3 (n=3), 4 (n=12), 5 (n=3). The studies were primarily conducted in United States of America, Australia, Canada, and European countries. From the grey literature search, 103 materials were determined to be topically relevant and were scanned for further information. Of these, a total of 22 were included in the final review, including 16 reports,^{1 3-5 39-49}(Aspex Consulting, Evaluation Framework and Initial Appraisal of PROMS: Final Report, personal communications, 2018) two book chapters,^{50 51} one dissertation,⁵² one forum proceeding document,⁵³ , one users guide,⁵⁴ and one research report.⁵⁵The summary of the included grey literature is available in table 2.

<insert Figure 1 here>

<insert Table 1 here>

<insert Table 2 here>

The following results are presented by research question.

1. What is best practice in the readability and feedback of PRO data to healthcare professionals?

Overall, the current evidence base provides some general guidance but inadequately describes specific optimal data display methods for the feedback of PRO data to healthcare professionals. From this review, several issues related to the reporting of PRO data to health professionals were explored and summarised, and recommendations identified to address these issues are provided below.

Authors from two publications suggested that in order to engage health professionals in reviewing PRO data, PRO reports need to be simplistic and easy to read.^{24 25} Suggested modifications to improve readability of feedback interventions included: reducing the number of metrics (i.e. outcomes) presented within a report, minimising page counts, avoiding 3-dimensional graphical elements, uncluttering reports to increase readability and including instructions where they will be needed.²⁹

Six publications addressed the issue of directionality of PRO scores in graphical displays.^{2 11 12 35 38 55} A consensus panel found that there was no intuitive interpretation of symptom scores, with some people expecting higher scores to mean ‘better’ and other people expecting higher scores to mean ‘more’ of the symptom (and therefore worse).¹¹ Healthcare professionals interpretation accuracy has been demonstrated to be greater for line graphs when higher scores indicated ‘better’ rather than indicating ‘more’.⁵⁵ Despite these results, caution should be taken when modifying the directionality of PROs in order for all symptom scores to have the same directionality, due to potential confusion associated with inconsistencies across instruments.¹¹ One suggestion to avoid potential confusion is to provide a label to denote ‘better’ alongside the chart to indicate the directionality of the PRO,^{2 38} or use coloured arrows; green for better scores, and red arrows for worse scores.³⁵

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Further, the provision of a written explanation of the PRO score alongside the graph, has also been recommended to assist with interpretation.²⁹ Written explanations are particularly valuable for complex graphical displays.^{31 37} Another suggestion is to include descriptive labels (e.g. mild/moderate/severe) alongside the chart, assuming data to support the use of these thresholds are available.^{11 27} The use of ‘traffic-light’ colours to colour-code the thresholds has also been recommended to allow a quick and easy review.^{30 34-36}

Displaying a reference population to use as a comparison was addressed in 4 publications.^{3 11 37 48}. Reference populations, such as national averages or relevant norm information for peer groups, can help provide context for the interpretation of the PRO scores,³⁷ provided these data are available.¹¹ However, there is a need to balance the complexity of presenting additional data and the healthcare professionals’ ability to understand the data.¹¹ Furthermore in an exploratory study participants warned that providing comparison data can have unintended consequences, such as negative comparisons leading to reputational damage when the health service or healthcare professional is reported to be lesser performing in their PROs results.³⁷

A cross-sectional mixed methods study in oncology reported that healthcare professionals indicated a preference towards the inclusion of statistical details for PRO data.⁶ There is a move away from reporting the p-value alone to illustrate statistical significance, and instead the use confidence intervals is encouraged.^{6 11} The clinically important difference should also be included within the graphical representation of the PRO results, where appropriate.^{11 25} Though an asterisk is not recommended to indicate clinically important differences, as that symbol is commonly used to indicate statistical significance.¹¹ Patients can find the inclusion of clinically important differences confusing,⁶ but it is valuable for them to know if the difference matters.¹¹

2. What PRO data presentation formats have the most utility for healthcare professionals?

There are many different formatting approaches that have been used to display PRO results. Table 3 provides a summary of different formats that have been utilised to display PRO data, as well as an indication of the preference among healthcare professionals. Line graphs and bar graphs were identified as the most familiar and preferred format among healthcare professionals for comparing and reviewing their service.

<insert Table 3 here>

3. Are there factors that influence PRO data interpretation or use in clinical practice?

Within the current body of literature several barriers and enablers associated with the use and uptake of PROs among healthcare professionals have been identified. However, the evidence base addressing these proposed challenges, or explicit recommendations to enable successful adoption of PROs among healthcare professionals, is limited.^{1 53} We identified seven factors that influence the interpretation of PROs: missing data, government and local leadership, healthcare professional education and training, engaging healthcare professionals to overcome resistance to change in clinical practice, casemix adjustment, interoperability of information and communication technology (ICT) systems, and frequency/timeliness of feedback.

Missing data.

Missing data poses a challenge with analysis and reporting of PRO results. Missing PRO data may be unavoidable due to a multitude of reasons. There may be specific population groups with missing PRO responses, or sensitive and difficult questions that may be omitted.⁵⁰ Consequently, these instances may result in scepticism about completeness of the data among healthcare professionals.⁵²

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Achievement of high participation and completion rates at follow-up, both individually and at the aggregate level influences overall usefulness of PRO data.³⁹ However, due to the complex nature of PROs and their inevitable incompleteness in certain cases, strong evidence through a statistical analysis plan may assist in ensuring the resulting analyses and reports are unaffected by missing data.⁵⁰

The role of government and local leadership.

It has been reported that ‘top-down’ approaches to PRO implementation whereby government or management is driving the implementation process and performing the assessment and taking actions based on the rules, may be met with resistance from healthcare professionals.⁴ These endeavours can be complemented with ‘bottom-up’ approaches where PRO implementation is clinically driven and is more focused on quality improvement.⁴ The use of the data from these collection approaches can be reported back at the micro level (to inform decision for individual patient care), as well as the meso level (to assess performance of services and quality improvement) or the macro level (to asses healthcare systems).^{4 5} Importantly, the most evidence for effectiveness of PRO feedback exists at the meso level.⁵

Further, clinical/local champions and stakeholder initiatives are crucial to enhance healthcare professionals’ engagement with collecting and use of PRO data.⁵³ Specifically, clinical champions may contribute to broader dissemination and use of PRO data among clinical units or within health services (Aspex Consulting, Evaluation Framework and Initial Appraisal of PROMS: Final Report, personal communications, 2018).

Healthcare professional education and training.

Healthcare professionals education and training was addressed in nine publications.^{32 39 41 42 45 49 51 54 55} Healthcare professionals may not understand PRO data or know what to do with the results.^{39 49} There is a need to increase PRO-specific training and education to aid healthcare professionals’ ability to; interpret PRO data, integrate the use of PROs into clinical practice,

and respond to concerning PRO results.^{41 51} There is currently no recommendation for how to direct healthcare professionals to use and interpret PRO data or for how to respond to concerning results in a standardised, clinically appropriate manner.^{39 54} For example, our review found the need for disease management pathways to be developed as a resource to respond to issues identified through PRO results.⁵⁴ Implementation of a PRO training course has been demonstrated to improve attitudes and self-efficacy from healthcare professionals towards PRO data within the child mental health services.³²

Engaging healthcare professionals to overcome resistance to change in clinical practice.

There may be a lack of buy-in among the clinical community when healthcare professionals are uncertain or lack confidence in understanding how PRO results could be used to improve their clinical practice.⁴² As such, PROs should be implemented in a way that can be directly translated into specific actions for healthcare professionals, with clear recommendations on how to respond to PRO scores in clinical settings.^{26 28} Additional recommendations to improve healthcare professional buy-in include: co-designing data display formats and information content with healthcare professionals' input to ensure the formats meet their needs,^{25 39 49} and showcasing benefits to help health professionals see the merits of using PRO data.^{30 47}

Analyses that include adjustment for differences in patient characteristics (casemix adjustment).

Due to the differing characteristics of patients admitted to different health services, comparing outcomes between hospitals without casemix adjustment may be misleading.⁵³ Casemix adjustments are particularly important to healthcare professionals.⁵³ Casemix adjustment uses statistical models to account for known variables that affect health (such as age, gender, ethnicity, symptom severity, and socio-economic background) to predict what each hospital's outcomes would be for a standard patient or population.¹ The development of

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casemix adjustment methods for PRO data are a widely recognised challenge in the field.^{1 48}

⁵³ For example, patients may be influenced by cultural, development or personality differences, contextual factors or life circumstances; and different health experiences or events when interpreting and responding to questions related to their health.⁵³ Importantly, casemix adjustment for PROs needs to be disease/condition-specific, since demographic factors that may influence patients’ responses to PROs are likely to vary across patient cohorts and clinical settings.⁴² Published evidence related to the development of casemix adjustment methods for PRO data is limited. Further development and refinement of robust casemix adjustment methods is required to guide meaningful interpretation and use of PRO data.^{1 43 53}

Interoperability of Information and Communication Technology (ICT) systems.

A lack of efficient, interoperable health information systems and robust data governance frameworks are a significant barrier to integration and reporting of PROs.^{44 48} ICT system interoperability issues prohibit patient-level linkage between datasets, impacting upon the ability to conduct risk-adjustments and draw meaningful conclusions from some PRO collections.⁴⁸

Frequency/timeliness of feedback.

The frequency or timelines of PRO feedback was addressed in 10 publications.^{3 5 29 30 37 45-47 52 53} Perceived time lags associated with PRO data feedback, such as reports fed back annually, may lead to information being discounted as irrelevant.^{29 45 53} One solution is to routinely report PRO results to healthcare professionals or provide the capacity for clinical teams to continuously retrieve and review their own data.^{46 52} Conversely, too much feedback could result in ‘alert fatigue’, which may lead healthcare professionals to ignore the PRO results.³⁰ Despite reporting delays as a known barrier to healthcare professionals uptake of PROs, optimal intervals for feedback have seldom been investigated in this area.²⁹ One

suggested timing for audit and feedback to professional practice is 1-4 times a year for process and outcome indicators, but more frequently where there is greater possibility for improvement.³⁷

A summary of the overall prevailing consensus-based guiding principles are outlined in Box 1.

<insert box 1>

DISCUSSION

PRO data may be used to improve the safety and quality of healthcare, but in order to achieve this, it is critical that feedback methods are optimised. This scoping review provides a novel summation of the published and grey literature of the guiding principles for effectively feeding back Patient Reported Outcome data to healthcare providers. The overall synthesis of the literature revealed various issues that provide opportunities to advance this field.

What constitutes ‘best practice’ feedback for PROs is not yet firmly established. Despite this gap in the evidence, we were able to highlight multiple prevailing consensus-based approaches.

Studies on the feedback of PRO data are limited, however there is a large body of literature that informs graphical presentation of clinical data in general. This extensive research can inform understanding for the graphic representation of PROs. For example, similar graphical display features have been demonstrated in other forms of feedback to clinicians. In a review of quality dashboards used in clinical settings Dowding et al (2015)⁵⁶ found that most dashboards used the ‘traffic light’ colour coding in their displays to indicate what type of action is required. Converse to the suggestions made in the current review, Dowding et al (2015)⁵⁶ found that most dashboards used a table format to represent the data.

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Providing peer group data or benchmarking to enable comparison of current in clinical audit and feedback is also a common technique to improve engagement.^{57 58}

To facilitate the successful uptake of PRO data in clinical practice it is also recommended that a knowledge translation strategy is developed.⁵⁹ Identification of local barriers and enablers and the development of a theory-based integrative knowledge translation plan may support greater uptake and use of PRO data. Further, recommendations to improve knowledge translation have been identified in other types of clinical audit and feedback. The authors from multiple clinical audit and feedback studies have indicated that feedback is more effective when there is a local champion.^{60 61} The timeliness and actionability of the feedback are other factors that are consistently mentioned for effective clinical feedback.^{58 60 62 63} These findings are in line with the current study. Additional factors to improve the effectiveness of feedback include: providing feedback both verbally and in written format, and using feedback to decrease rather than increase certain behaviours.⁶⁰

There have also been several initiatives to develop guidance on communicating data in general, which can further inform the development of PRO data feedback. In a guide published by authors from the National Cancer Institute,⁶⁴ several suggestions for how to present data effectively are given, and multiple are in line with the current review, including: the use of labels and the use of colour. There are also additional suggestions including: the use of verbal qualifiers or metaphors to help explain the meaning of the numbers and rounding most decimals to the nearest whole number for ease of understanding. Simpson (2015) provides guidance for how to choose the appropriate graph type.⁶⁵ Nominal and ordinal data can be displayed using a pie graph or car chart, but interval and ratio data may have too many categories to be displayed in a pie chart. Further, box plots are best used to display variables that are not normally distributed.

Strengths of our review included that each reviewer used a pre-defined protocol and the information from the included literature was summarised using a template to ensure consistency. Despite our rigorous search strategy, several limitations deserve comment. Due to the available timeframe both the academic and grey literature search and screening process were largely conducted by a single reviewer. This may have resulted in selection and interpretation bias as some relevant literature may have been overlooked. Further, the grey literature search was limited to only seven countries. Despite this limitation, it is reasonable to assume that, much like the standards available for the presentation of data in other healthcare settings, the general guiding principles for PRO data feedback would be consistent across jurisdictions and between countries. Overall, we found limited high-quality published evidence related to optimal feedback methods and formats for PRO data. Our findings here suggest that there is a need for more rigorous testing of PRO feedback methods in the future.

Future directions

PROs represent a key building block required to move towards a health system that can assess the value of healthcare from a consumer's perspective (Paxton Partners, Patient-Reported Outcome Measures: Literature scan, personal communication, 2018). Little is known about the best way to feedback PRO data effectively to healthcare providers in considering the performance of their health services compared with peer services. We sought to summarise the current evidence base and use this information to facilitate a process to determine the best methods for future implementation of PROs reporting. As part of planned future work associated with the AuSCR^{13 66} we seek to test various formats based on our findings and extend the work conducted to date. AuSCR is one of the few national stroke clinical registries around the world to collect PROs.¹⁸ The outcome of this work will also inform the field and may be adopted by other Clinical Quality Registries.

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Conclusion

While ‘best practice’ feedback methods and presentation formats of PRO data to healthcare professionals are emerging, there remains many unanswered questions. The basic guiding principles and recommendations presented in the body of the current review draw upon the findings of the prevailing, consensus-based literature. Further research is required to determine what healthcare professionals perceive to be simple, easy-to-read and interpretable PRO reports for aggregated data. Healthcare professionals require support to interpret the data and should be part of the process of co-designing formats that will be the most meaningful to them. Our work here provides some guidance towards these efforts.

References

1. Canadian Institute for Health Information (CIHI). Health outcomes of care: An idea whose time has come. Ottawa, Ontario., 2012:1-52.
2. Brundage M, Blackford A, Tolbert E, et al. Presenting comparative study PRO results to clinicians and researchers: Beyond the eye of the beholder. *Quality of Life Research* 2018;27(1):75-90. doi: 10.1007/s11136-017-1710-6
3. Thompson C, Sansoni J, Morris D, et al. Patient-reported Outcome Measures: An environmental scan of the Australian healthcare sector. ACSQHC: Sydney, NSW: Australian Commission on Safety and Quality in Health Care, 2016:89.
4. Desomer A, Van Den Heede K, Triemstra M, et al. Use of patient-reported outcome and experience measures in patient care and policy: Belgian Health Care Knowledge Centre, 2018:1-151.
5. Williams K, Sansoni J, Morris D, et al. Patient-reported outcome measures: Literature review. ACSQHC: Sydney, NSW: Australian Commission on Safety and Quality in Health Care, 2016:1-91.
6. Brundage MD, Smith KC, Little EA, et al. Communicating patient-reported outcome scores using graphic formats: Results from a mixed-methods evaluation. *Quality of Life Research* 2015;24(10):2457-72. doi: 10.1007/s11136-015-0974-y
7. Santana MJ, Haverman L, Absolom K, et al. Training clinicians in how to use patient-reported outcome measures in routine clinical practice. *Quality of Life Research* 2015;24(7):1707-18. doi: 10.1007/s11136-014-0903-5
8. Ahmed S, Berzon RA, Revicki DA, et al. The use of patient-reported outcomes (PRO) within comparative effectiveness research: Implications for clinical practice and health care policy. *Medical Care* 2012;50(12):1060-70. doi: 10.1097/MLR.0b013e318268aaff

9. Proding B, Taylor P. Improving quality of care through Patient-Reported Outcome Measures (PROMs): Expert interviews using the NHS PROMs Programme and the Swedish quality registers for knee and hip arthroplasty as examples. *BMC Health Services Research* 2018;18:1-13. doi: 10.1186/s12913-018-2898-z
10. Brundage M, Bass B, Jolie R, et al. A knowledge translation challenge: Clinical use of quality of life data from cancer clinical trials. *Quality of Life Research* 2011;20(7):979-85.
11. Snyder C, Smith K, Holzner B, et al. Making a picture worth a thousand numbers: Recommendations for graphically displaying patient-reported outcomes data. *Quality of Life Research* 2019;28(2):345-56. doi: 10.1007/s11136-018-2020-3
12. Arcia A, Woollen J, Bakken S. A systematic method for exploring data attributes in preparation for designing tailored infographics of patient reported outcomes. *eGEMs* 2018;6(1):1-9. doi: 10.5334/egems.190
13. Cadilhac DA, Lannin NA, Anderson CS, et al. Protocol and pilot data for establishing the Australian Stroke Clinical Registry. *International Journal of Stroke* 2010;5(3):217-26. doi: 10.1111/j.1747-4949.2010.00430.x
14. Peters M, Godfrey C, McInerney P, et al. Chapter 11: Scoping Reviews (2020 version). In: Aromataris E MZ, ed. JBI Manual for Evidence Synthesis. Adelaide: JBI 2020.
15. Cochrane Training. Online learning 2019 [Available from: <https://training.cochrane.org/online-learning> accessed June 2019.
16. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine* 2018;169(7):467-73. doi: 10.7326/M18-0850
17. Covidence systematic review software, [program]. Melbourne, Australia: Veritas Health Innovation.

- 1
2
3 18. Cadilhac DA, Kim J, Lannin NA, et al. National stroke registries for monitoring and
4
5 improving the quality of hospital care: A systematic review. *International Journal of*
6
7 *Stroke* 2015;11(1):28-40. doi: 10.1177/1747493015607523
8
9
- 10 19. Campbell BCV, Ma H, Ringleb PA, et al. Extending thrombolysis to 4·5–9 h and wake-
11
12 up stroke using perfusion imaging: a systematic review and meta-analysis of
13
14 individual patient data. *The Lancet* 2019;394(10193):139-47. doi:
15
16 [https://doi.org/10.1016/S0140-6736\(19\)31053-0](https://doi.org/10.1016/S0140-6736(19)31053-0)
17
18
- 19 20. Lynch E, Hillier S, Cadilhac D. When Should Physical Rehabilitation Commence after
20
21 Stroke: A Systematic Review. *International Journal of Stroke* 2014;9(4):468-78. doi:
22
23 10.1111/ijss.12262
24
25
- 26 21. Joanna Briggs Institute. JBI Levels of Evidence 2014 [Available from:
27
28 [https://joannabriggs.org/sites/default/files/2019-05/JBI-Levels-of-](https://joannabriggs.org/sites/default/files/2019-05/JBI-Levels-of-evidence_2014_0.pdf)
29
30 [evidence_2014_0.pdf](https://joannabriggs.org/sites/default/files/2019-05/JBI-Levels-of-evidence_2014_0.pdf) accessed June 2019.
31
32
- 33 22. Joanna Briggs Institute Reviewer's Manual: The Joanna Briggs Institute 2017.
34
35
- 36 23. Moher D, Liberati A, Tetzlaff J, et al. Preferred Reporting Items for Systematic Reviews
37
38 and Meta Analyses: The PRISMA Statement. *PLoS Med* 2009;6(7):e1000097. doi:
39
40 doi:10.1371/journal.pmed1000097
41
42
- 43 24. Bantug ET, Coles T, Smith KC, et al. Graphical displays of patient-reported outcomes
44
45 (PRO) for use in clinical practice: What makes a pro picture worth a thousand words?
46
47 *Patient Education and Counseling* 2016;99(4):483-90. doi:
48
49 <http://dx.doi.org/10.1016/j.pec.2015.10.027>
50
51
- 52 25. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using
53
54 information from patient-reported outcome measures to improve the quality of
55
56 healthcare: A systematic review of qualitative research. *BMJ Quality & Safety*
57
58 2014;23(6):508. doi: 10.1136/bmjqs-2013-002524
59
60

- 1
2
3 26. Forsberg HH, Nelson EC, Reid R, et al. Using patient-reported outcomes in routine
4 practice: Three novel use cases and implications. *Journal of Ambulatory Care*
5
6 *Management* 2015;38(2):188-95. doi: 10.1097/JAC.000000000000052
7
8
9
10 27. Oliver BJ, Nelson EC, Kerrigan CL. Turning feed-forward and feedback processes on
11 patient-reported data into intelligent action and informed decision-making: Case
12 studies and principles. *Medical Care* 2019;57 (Supplement 1):S31-S37. doi:
13
14 <https://dx.doi.org/10.1097/MLR.0000000000001088>
15
16
17
18 28. Jensen RE, Snyder CF, Basch E, et al. All together now: Findings from a PCORI
19 workshop to align patient-reported outcomes in the electronic health record. *Journal*
20 *of Comparative Effectiveness Research* 2016;5(6):561-67. doi: 10.2217/ce-2016-
21 0026
22
23
24 29. Brehaut J, Colquhoun H, Eva K, et al. Practice Feedback Interventions: 15 Suggestions
25 for Optimizing Effectiveness. *Annals of Internal Medicine* 2016;164(6):435-41. doi:
26 10.7326/M15-2248
27
28
29 30. Aiyegbusi OL, Kyte D, Cockwell P, et al. Patient and clinician perspectives on electronic
30 patient-reported outcome measures in the management of advanced CKD: A
31 qualitative study. *American Journal of Kidney Diseases* 2019;74(2):167-78. doi:
32 10.1053/j.ajkd.2019.02.011
33
34
35 31. Allwood D, Hildon Z, Black N. Clinicians' views of formats of performance comparisons.
36 *Journal of Evaluation in Clinical Practice* 2013;19(1):86-93. doi: 10.1111/j.1365-
37 2753.2011.01777.x
38
39
40 32. Edbrooke-Childs J, Wolpert M, Deighton J. Using Patient Reported Outcome Measures to
41 Improve Service Effectiveness (UPROMISE): Training clinicians to use outcome
42 measures in child mental health. *Administration and Policy in Mental Health and*
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- Mental Health Services Research* 2016;43(3):302-08. doi: 10.1007/s10488-014-0600-2
33. Hartzler AL, IZard JP, Dalkin BL, et al. Design and feasibility of integrating personalized PRO dashboards into prostate cancer care. *Journal of the American Medical Informatics Association* 2016;23(1):38-47. doi: 10.1093/jamia/ocv101
34. Hildon Z, Allwood D, Black N. Making data more meaningful: Patients' views of the format and content of quality indicators comparing health care providers. *Patient Education and Counseling* 2012;88(2):298-304. doi: 10.1016/j.pec.2012.02.006
35. Kuijpers W, Giesinger JM, Zubernigg A, et al. Patients' and health professionals' understanding of and preferences for graphical presentation styles for individual-level EORTC QLQ-C30 scores. *Quality of Life Research* 2016;25(3):595-604. doi: 10.1007/s11136-015-1107-3
36. Talib TL, DeChant P, Kean J, et al. A qualitative study of patients' perceptions of the utility of patient-reported outcome measures of symptoms in primary care clinics. *Quality of Life Research* 2018;27(12):3157-66. doi: 10.1007/s11136-018-1968-3
37. van Overveld LFJ, Takes RP, Vijn TW, et al. Feedback preferences of patients, professionals and health insurers in integrated head and neck cancer care. *Health Expectations* 2017;20(6):1275-88. doi: 10.1111/hex.12567
38. Wu AW, White SM, Blackford AL, et al. Improving an electronic system for measuring PROs in routine oncology practice. *Journal of cancer survivorship : research and practice* 2016;10(3):573-82. doi: <http://dx.doi.org/10.1007/s11764-015-0503-6>
39. Nelson E, Hvitfeldt H, Reid R, et al. Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case studies from Dartmouth, Karolinska and Group Health. Lebanon, New Hampshire: The Dartmouth Institute for Health Policy and Clinical Practice, 2012:1-55.

1
2
3
4
5
6
7
8
9
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41
42
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45
46
47
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50
51
52
53
54
55
56
57
58
59
60

40. Duckett S, Cuddihy M, Newnham H. Targeting zero: Supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care - report of the Review of Hospital Safety and Quality Assurance in Victoria. Melbourne: State Government of Victoria; , 2016.

41. Clinical Oncology Society of Australia (COSA). Implementing monitoring of patient-reported outcomes into cancer care in Australia - A COSA Think Tank Report. Sydney, Australia: Clinical Oncology Society of Australia,, 2018.

42. Chen J. Integrated Care: Patient reported outcome measures and patient reported experience measures - A rapid scoping review. Sydney: NSW Agency for Clinical Innovation, 2015:1-116.

43. Franklin P, Chenok K, Lavalee D, et al. Framework to guide the collection and use of Patient-Reported Outcome Measures in the learning healthcare system. *Generating Evidence & Methods to improve patient outcomes* 2017;5(1):17. doi: 10.5334/egems.227

44. Batalden P, Corrigan, J, Harrison, W, Kerrigan, C and Øvretveit, J. Enabling uptake of a registry-supported care and learning system in the United States: A report to the Robert Wood Johnson Foundation from Karolinska Institutet and The Dartmouth Institute, 2014.

45. Canadian Institute for Health Information (CIHI). Patient-centred measurement and reporting in Canada launching the discussion toward a future state. Ottawa, Ont., 2017:1-46.

46. NSW Agency for Clinical Innovation. Patient Reported Measures – Program overview. Chatswood: ACI, NSW, 2018:18.

47. Canadian Institute for Health Information (CIHI). PROMs Background Document. Ottawa, Ontario, 2015:1-38.

- 1
2
3 48. World Economic Forum. Value in healthcare laying the foundation for health system
4 transformation. Cologny/Geneva, Switzerland: World Economic Forum, 2017:1-40.
5
6
7
8 49. Duckett S, Jorm C, Danks L. Strengthening Safety Statistics: How to make hospital safety
9 data more useful: The Grattan Institute, 2017.
10
11
12 50. Cappelleri J, Zou K, Bushmakina A, et al. Patient-Reported Outcomes: Measurement,
13 Implementation and Interpretation. Boca Raton, FL: CRC Press 2014.
14
15
16 51. Raine R, Fitzpatrick R, Barratt H, et al. Patient-reported outcome measures and the
17 evaluation of services. Challenges, solutions and future directions in the evaluation of
18 service innovations in health care and public health: National Institute for Health
19 Research 2016.
20
21
22
23
24
25 52. Peterson A. Learning and understanding for quality improvement under different
26 conditions - An analysis of quality registry-based collaboratives in acute and chronic
27 care. Jönköping University, 2015.
28
29
30
31
32 53. Canadian Institute for Health Information (CIHI). CIHI PROMs Forum Proceedings.
33 Ottawa, Ontario, 2015:41.
34
35
36 54. Aaronson N, Elliott T, Greenhalgh J, et al. User's Guide to Implementing Patient-
37 Reported Outcomes Assessment in Clinical Practice. Version 2: January 2015:
38 International Society for Quality of Life Research 2015:1-47.
39
40
41
42 55. Snyder C, Brundage M, Smith KC, et al. Testing Ways to Display Patient-Reported
43 Outcomes Data for Patients and Clinicians. Washington, DC: Patient-Centered
44 Outcomes Research Institute (PCORI), 2018:1-163.
45
46
47
48
49
50 56. Dowding D, Randell R, Gardner P, et al. Dashboards for improving patient care: Review
51 of the literature. *International Journal of Medical Informatics* 2015;84(2):87-100. doi:
52 <https://doi.org/10.1016/j.ijmedinf.2014.10.001>
53
54
55
56
57
58
59
60

57. Ray-Barruel G, Ullman AJ, Rickard CM, et al. Clinical audits to improve critical care: Part 2: Analyse, benchmark and feedback. *Australian Critical Care* 2018;31(2):106-09. doi: <https://doi.org/10.1016/j.aucc.2017.04.002>
58. Colquhoun H, Michie S, Sales A, et al. Reporting and design elements of audit and feedback interventions: a secondary review. *BMJ Quality & Safety* 2017;26(1):54. doi: 10.1136/bmjqs-2015-005004
59. Eilayyan O, Visca R, Zidarov D, et al. Developing theory-informed knowledge translation strategies to facilitate the use of patient-reported outcome measures in interdisciplinary low back pain clinical practices in Quebec: mixed methods study. *BMC Health Services Research* 2020;20(1):789. doi: 10.1186/s12913-020-05616-5
60. Ivers N, Jamtvedt G, Flottorp S, et al. Audit and feedback: Effects on professional practice and healthcare outcomes. *Cochrane Database of Systematic Reviews* 2012(6) doi: 10.1002/14651858.CD000259.pub3
61. Christina V, Baldwin K, Biron A, et al. Factors influencing the effectiveness of audit and feedback: nurses' perceptions. *Journal of Nursing Management* 2016;24(8):1080-87. doi: 10.1111/jonm.12409
62. Payne VL, Hysong SJ. Model depicting aspects of audit and feedback that impact physicians' acceptance of clinical performance feedback. *BMC Health Services Research* 2016;16(1):260-72. doi: 10.1186/s12913-016-1486-3
63. Hysong SJ, Best RG, Pugh JA. Audit and feedback and clinical practice guideline adherence: Making feedback actionable. *Implementation Science* 2006;1(1):9. doi: 10.1186/1748-5908-1-9
64. National Cancer Institute. Making data talk: A workbook. In: U.S. Department of Health and Human Services, ed. USA: National Institute of Health 2011.

- 1
2
3 65. Simpson SH. Creating a data analysis plan: What to consider when choosing statistics for
4 a study. *Can J Hosp Pharm* 2015;68(4):311-17. doi: 10.4212/cjhp.v68i4.1471
5
6
7
8 66. Cadilhac Dominique A, Andrew Nadine E, Lannin Natasha A, et al. Quality of acute care
9 and long-term quality of life and survival. *Stroke* 2017;48(4):1026-32. doi:
10 10.1161/STROKEAHA.116.015714
11
12
13
14
15
16
17
18
19
20
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For peer review only

Table 1. Characteristics of the included academic literature

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Aiyegbusi et al, ³⁰ 2019, UK	Semi-structured interviews and focus groups	Chronic kidney disease	12 patients with chronic kidney disease, and 22 healthcare professionals (nurses, psychologist, nephrologist, registrars and surgeons)	Thematic analysis of participants views on the use of a PROM system	Healthcare professionals suggested graphical representations of PROM feedback (rather than numeric), and to include “traffic light” colour-coding for quick and easy review. Healthcare professionals believed that "alert fatigue" from PROM feedback could be a barrier to use of PROM data, with the numerous alerts being provided to healthcare professionals encouraging them to ignore the PROM results.	Q1 Q3	Level 4	Moderate
Allwood et al, ³¹ 2013, UK	Structured focus groups	All healthcare areas	107 healthcare professionals (including consultants, junior doctors, nurses and allied health professionals)	Thematic analysis of participants comprehension and format preference for PROM data.	Healthcare professionals were generally positive about the use of bar charts and caterpillar plots for the display of PROM results. Opinions were mixed for the use of tables, funnel plots, and spider plots. Healthcare professionals found that tables with icons were insufficient.	Q1 Q2	Level 4	High
Arcia et al, ¹² 2018, USA	Case study	Unspecified	2 case studies of PRO feedback projects	Explore methods affecting the design decisions of PRO feedback projects	Summarises considerations that must be understood for the visualisation of PRO data, including the range and direction of scoring.	Q1	Level 4	Very low
Bantung et al, ²⁴ 2016	Integrated literature review, dates: 1999-2014	Oncology	9 included studies	Exploring the interpretation of graphic presentations of PRO data in clinical practice	HRQOL PROs can be accurately interpreted by healthcare professionals and patients; line graphs and bar charts were the most preferred format for PROs; patients prefer simple graphs, while healthcare professionals prefer simple graphs with confidence intervals	Q1 Q2	Level 4	High

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Boyce et al, ²⁵ 2014	Systematic review, dates: Up to 2012	All healthcare areas	16 included studies	Summarise qualitative studies that explore the experience of healthcare professionals using PROMs	Healthcare professionals value PROMs if they can be used to aid decision making. They appreciate graphical presentations that clearly depict clinically important changes. However, they can question whether the PROM data produced is an accurate reflection of care. Attitude towards the use of PROMs may be improved by engaging the healthcare professionals in the planning stage of PROMs introduction.	Q1 Q3	Level 4	High
Brehaut et al, ²⁹ 2016, Canada	Opinion	All healthcare areas	68 included studies	Identify suggestions for designing and delivering effective feedback interventions	Barriers: the use of unnecessary three-dimensional graphical elements which can clutter the display and bias the interpretation of the underlying information. Enablers: closely linking visual displays with summary messages, minimization of extraneous cognitive load for target audiences, the provision of short, actionable messages combined with optional detail and addressing the credibility of the data source used to produce the feedback.	Q1 Q3	Level 5	Low
Brundage et al, ⁶ 2015, USA	Survey followed by a semi-structured interview	Cancer	50 patients with cancer, and 20 oncology healthcare professionals (doctors and nurses)	Explore interpretation accuracy, ratings of ease-of understanding and usefulness of graphical formats. The interview explored helpful and confusing format attributes.	Both patients and healthcare professionals prefer line graphs across group-level data and individual-level data formats (compared with bar charts and cumulative distributions), but healthcare professionals prefer greater detail (i.e. statistical details) for group-level data.	Q1 Q2	Level 3	Moderate

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Brundage et al, ² 2018, USA	Survey followed by an interview with healthcare professionals	Cancer	233 healthcare professionals and 248 PRO researchers	Explore interpretation accuracy and clarity ratings of graphical formats and difference score representations.	Participants were accurate in their interpretation of PRO line graphs when the directionality of the score was indicated with a label “better”. Participants were more accurate in their interpretation of pie charts compared with bar graphs, for the display of proportions.	Q1 Q2	Level 3	Very High
Edbrooke-Childs et al, ³² 2016, UK	Pre-post observational study	Child mental Health	48 healthcare professionals attended the 1-day training course, 17 healthcare professionals attended the 3-day training course	Evaluate the effect of the training courses on attitudes and self-efficacy towards PROMs and feedback.	Increased time and duration of PROMS training showed greater improvement in attitudes towards PROMS, feedback attitudes and PROM self-efficacy.	Q1 Q3	Level 3	Moderate
Forsberg et al, 2015, ²⁶ USA & Sweden	Case study	Pain and spin conditions, rheumatology, and private healthcare	3 case studies of PRO feedback used in routine practice	Describe the principles and lessons learned from using PROs in the 3 case studies.	Healthcare professionals need to be able to place the PRO results within the context of the patient’s current clinical state, prognosis, and attitudes (e.g. a patient’s health status may be declining despite receiving best care). Healthcare professionals need to know what to do with the results, such as when the results are suggesting a significant health problem.	Q3	Level 4	High

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Hartzler et al, ³³ 2016, USA	Preliminary focus groups and interviews, followed by a pre-post study	Prostate cancer	The focus group included 60 prostate cancer survivors. 50 patients and 50 providers completed the interviews. 12 patients completed the pre-post observation	The focus groups assessed the needs of patients in relation to PROM feedback. The interviews evaluated preferred feedback methods. The pre-post study evaluated self-efficacy, satisfaction, communication, and compliance with the PRO dashboard.	Patients prioritized needs for dashboards to compare longitudinal trends and provide comparative groups. Patients and providers preferred bar charts and line graphs compared with tables and pictographs.	Q1 Q2	Level 2	Low
Hildon et al, ³⁴ 2012, UK	Focus groups	Knee surgery	45 patients who were planning or had undergone knee surgery	Thematic analysis of patients preferred PROM format.	Patients were generally positive about the use of bar charts and caterpillar plots. Opinions were mixed for tables and tables with icons. Patients did not like funnel plots. Patients liked the use of 'traffic-light' colours scheme and did not like the use of confidence intervals.	Q1 Q2	Level 4	High

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB I Level of Evidence	Strength of Evidence
Jensen et al, ²⁸ 2016, USA	Workshop proceedings	All healthcare areas	519 participants (including patients, healthcare professionals, researchers, healthcare system leaders and policy makers) attended the workshop, either in-person or online	Summary of workshop outcomes	Healthcare professionals should be provided with guidance in interpreting PRO scores, as they may not know the meaning of just raw scores. Translate PROs into specific actions for healthcare professionals by establishing clear recommendations on how to respond to PRO scores in clinical settings.	Q3	Level 5	High
Kuijpers et al, ³⁵ 2016, UK, Netherlands, Austria & Poland	Questionnaire	Cancer	548 patients with cancer and 227 healthcare professionals (doctors and nurses)	Understanding of PROM scores and preferences for different formats	Patients had no preference between non-colours bar charts and non-coloured line graphs. Patients preferred coloured bar charts over coloured line graphs. Healthcare professionals showed a preference for line graphs with ‘traffic-light’ coloured thresholds. Understanding did not differ between graphical formats for patients or healthcare professionals.	Q1 Q2	Level 4	High
Oliver et al, ²⁷ 2019, Australia, USA & Sweden	Case study	Multiple sclerosis, spinal care, and rheumatology	3 case studies of PRO feedback used in routine practice	Features that aid in the interpretation of PROs in the 3 case studies	The use of colour coding and threshold indicators, linked decision support functions (such as predictive calculators) can aid interpretation of PRO scores.	Q1	Level 4	Very low

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JB1 Level of Evidence	Strength of Evidence
Snyder et al, ¹¹ 2019, USA	Consensus panel	Cancer	Participants included healthcare professionals, PRO researchers, patients and caregivers. 28 participants in meeting 1, and 27 participants in meeting 2 (participants were not mutually exclusive)	A modified Delphi process to develop recommendations for PRO data display.	Recommendations for the display of PRO data include using labelling and thresholds, not mixing score direction in a single display, accommodating both normed and non-normed scoring, displaying confidence intervals, indicating possibly concerning results.	Q1 Q2	Level 5	High
Tabil et al, ³⁶ 2018, USA	Interview	Primary care	23 patients in primary care	Thematic analysis of the patient's perception of the utility of PRO in primary care.	The patients found the colour coding severe symptoms useful but recommended the addition of 'traffic-light' colour scheme.	Q1	Level 4	High
van Overveld et al, ³⁷ 2017, Netherlands	Semi-structured interview	Head and Neck	37 patients, healthcare professionals (doctors, nurses, speech pathologist, dietician, allied health), and health insurers.	Content analysis of participants preferred PRO feedback method.	Patients want PRO feedback to include explanations of how to read the PRO graph, the inclusion of a comparison, and the feedback delivered around once a year. Healthcare professionals want PRO feedback to be simple and include a comparison groups (such as national average, best and worst performer). Healthcare professionals want PRO feedback between 1-4 times a year and receive the feedback via email.	Q1 Q2 Q3	Level 4	High

Author, year, country	Study method	Clinical Area	Number of participants or included studies	Study aim/design	Relevant Findings	Review question related to	JBIC Level of Evidence	Strength of Evidence
Wu et al, ³⁸ 2016, USA	Semi-structured interview	Cancer	42 cancer patients and 12 healthcare professionals (doctors and nurses)	Evaluate participants views of a webtool that was designed to allow PRO use in clinical practice.	Patients and healthcare professionals recommended having PRO score directionality be consistent, and more explanation of the score meaning. Healthcare professionals also recommended including if the score indicates better or worse health.	Q1	Level 4	High

Note. JBI = Joanna Briggs Institute. PRO = Patient reported outcome. PROM = Patient reported outcome measure. USA = United States of America. UK = United Kingdom.

Table 2. Characteristics of the included grey literature

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Aaronson et al. User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice. Version 2: January 2015. ⁵⁴	http://www.isoqol.org/UserFiles/2015UsersGuide-Version2.pdf	User's guide	09 July 2019	<p>A User's Guide developed by a team from the International Society for Quality of Life Research to provide practical guidance for clinicians with an interest in using PRO data in clinical practice. A combination of different tools to facilitate PRO data interpretation were recommended, and their advantages and disadvantages were described. Recommended (e.g. tools to aid PRO data interpretation vary depending on whether the patient's current score or a change in score is fed back).</p> <ul style="list-style-type: none"> Barriers: a lack of familiarity with PRO data among clinicians, time and resource constraints, fitting the use of PRO data within existing clinical workflows. Enablers: the provision of simple written guidance of PRO scoring meaning (e.g. higher scores mean better functioning) can provide a general indication of the meaning of scores, but will not provide information about the clinical importance of results.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Batalden et al. Enabling uptake of a registry-supported care and learning system in the United States: A report to the Robert Wood Johnson Foundation from Karolinska Institutet and The Dartmouth Institute, 2014. ⁴⁴	http://srq.nu/wp-content/uploads/2014/10/Summary-Report-4-30-14-FINAL.pdf	Technical report	10 July 2019	<p>The authors outlined a synergistic, learning health system model based on a case study from the Swedish Rheumatology Quality (SRQ) Registry whereby several data feedback systems were involved. PRO data were fed forward in a shared information environment and combined with clinical data displayed on a dashboard for outcome evaluation and clinical decision-making</p> <ul style="list-style-type: none">Barriers: a lack of interoperability between health information systems coupled with administrative workloads for clinicians, time and resource constraints in clinical practice.Enablers: creating seamless exchange of PRO data across health information platforms, the creation of PROs terminology and data exchange standards to facilitate point-of-care data solutions.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Canadian Institute for Health Information (CIHI). Health outcomes of care: An idea whose time has come, 2012. ¹	https://secure.cihi.ca/free_products/HealthOutcomes2012_EN.pdf	Technical report	23 July 2019	<p>A report produced by authors from Statistics Canada and the Canadian Institute for Health Information which presented PRO data developments options (using several case studies) to address gaps related to health outcomes. The authors included information related to challenges involved with the use of PROs among healthcare professionals.</p> <ul style="list-style-type: none"> Barriers: concerns related to the need for additional time and resources to facilitate uptake of PROs among clinicians. Enablers: engagement of clinicians, the implementation of incentives to encourage use of PRO data, and the need for further research related to casemix adjustment methods for PRO data.
Canadian Institute for Health Information (CIHI). PROMs Background Document, 2015. ⁴⁷	https://www.cihi.ca/sites/default/files/document/proms_background_may21_en-web.pdf	Report	23 July 2019	<p>The authors provided an overview of the coordinated approach to PROMs collection and reporting established in Canada, including the initial implementation steps and a review of the international PROMs landscape.</p> <ul style="list-style-type: none"> Barriers: a lack of collection of risk adjustment variables and data linkage processes for PRO data. Enablers: implementation of a coordinated, timely reporting approach and the ability to produce comparable PRO data report formats (across jurisdictions) to drive system improvements.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Canadian Institute for Health Information (CIHI). CIHI PROMs Forum Proceedings, 2015. ⁵³	https://www.cihi.ca/sites/default/files/document/proms_forum_proceedings_-_may_26_enweb.pdf	Forum Proceedings	23 July 2019	<p>An outline of the proceedings from a PROMs Forum hosted by the Canadian Institute for Health Information. In brief, the value of targeting PROs data initiatives towards clinicians was outlined, including three clinical areas (e.g. renal care) in which well-established PROs reporting mechanisms were determined to be most desirable.</p> <ul style="list-style-type: none">Barriers: a lack of timeliness for PRO data reporting, data capture delays, reporting biases, and a lack of establishment of PRO outcome thresholds/performance targets were identified as a challenge for engaging clinicians.Enablers: leveraging existing infrastructure to facilitate collection and reporting of PROs data and the engagement of clinical champions which were identified as success factors for PROMs initiatives.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Canadian Institute for Health Information (CIHI). Patient-centred measurement and reporting in Canada launching the discussion toward a future state, 2017. ⁴⁵	https://www.cihi.ca/sites/default/files/document/visioning-day-paper-en-web.pdf	Technical report	26 July 2019	<p>The authors presented a summary report based on presentations delivered at an invitational visioning day hosted by the Canadian Institute for Health Information. In brief, a common set of priorities for measurement and reporting of PRO data were highlighted among 33 participants.</p> <ul style="list-style-type: none"> Barriers: a lack of cross-country coordination of PRO data initiatives and limited capacity for clinicians/services/systems to compare results internationally. Enablers: provision of PRO data education, guidelines and work tools targeted towards clinicians to help with the interpretation of routinely reported PRO results and to understand how to improve care delivery.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Cappelleri et al. Patient-Reported Outcomes: Measurement, Implementation and Interpretation, 2014 ⁵⁰ .	https://www.crcpress.com/Patient-Reported-Outcomes-Measurement-Implementation-and-Interpretation/Cappelleri-Zou-Bushmakina-Alvir-Alemayehu-Symonds/p/book/9781138199590	Book/Book chapter	17 July 2019	<p>The authors provided a comprehensive overview of various PRO data elements (e.g. measurement validity/reliability, missing data and statistical techniques) that can be used to advance the validation and use of these data.</p> <ul style="list-style-type: none">Barriers: issues associated with missing data and response-shift bias were highlighted for PRO datasets. The authors suggested the use of a statistical analysis plan to ensure analyses/reports are insensitive to missing data.Enablers: electronic data capture to minimise missing PRO data, the use of descriptive statistics for presenting PRO scores, exploring the distribution of PRO datasets as an essential elements of data summarization.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Chen J. Integrated Care: Patient reported outcome measures and patient reported experience measures - A rapid scoping review, 2015. ⁴²	https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0009/281979/ACI_Proms_Premis_Report.pdf	Technical report	08 July 2019	<p>A report based on the outcomes of a scoping review that was undertaken to examine the issues of implementing a large-scale PROMs initiative, with a particular focus on patient-centre care in New South Wales, Australia.</p> <ul style="list-style-type: none"> Barriers: issues related to the phenomenon of response shift for PRO data and a lack of established clinically meaningful cut-offs (e.g. particularly for longitudinal data). The author included several analytical methods that can be used to identify these issues. Enablers: stakeholder engagement and generating clinical 'buy-in' may enable uptake and use of PRO data if clinicians are educated and trained to understand the relevance of these data and their use for quality improvement purposes.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Clinical Oncology Society of Australia (COSA). Implementing monitoring of patient-reported outcomes into cancer care in Australia - A COSA Think Tank Report, 2018. ⁴¹	https://www.cosa.org.au/media/332504/cosa_pros_think_tank_report_final.pdf	Technical report	12 July 2019	<p>A report based on the findings from a Think Tank that involved 32 participants and was focussed on approaches to embed PRO assessment as part of routine cancer care in Australia. The authors highlighted effective methods for implementing PRO monitoring and discussed the benefits of using PRO data in clinical practice.</p> <ul style="list-style-type: none">Barriers: a lack of awareness of PROs and perceptions of risk among clinicians, system-level issues (e.g. limited resources, variability of information technology systems), the alteration of clinical workflows to facilitate use of PROs.Enablers: education and training for clinicians (e.g. why PRO data are important, how to use these data as part of clinical practice) and engaging clinical champions.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Desomer et al. Use of patient-reported outcome and experience measures in patient care and policy. Belgian Health Care Knowledge Centre, 2018. ⁴	https://kce.fgov.be/en/use-of-patient-reported-outcome-and-experience-measures-in-patient-care-and-policy	Technical Report	26 July 2019	<p>A report based on an evaluation of the uses, benefits, barriers and facilitators of patient-reported outcome and experience measures in clinical practice undertaken by a research team from the Belgian Health Care Knowledge Centre (KCE). The authors included an analysis of international initiatives and a review of the peer-reviewed literature along with a set of recommendations to facilitate the introduction of PROs.</p> <ul style="list-style-type: none"> Barriers: PRO data selection bias (e.g. due to cultural or language barriers), lack of interoperability between information technology systems, data reporting time delays, a lack of knowledge about the value of PROs and perceived administrative burden among clinicians. Enablers: using a bottom-up (clinically driven) approach combined with top-down guidance (policy driven) to improve use of PROs in clinical practice, accessible data infrastructure (e.g. interactive tools for analyses and data visualization) and easy to read reports linked to concrete actions for clinicians.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Duckett et al. Targeting zero: Supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care - report of the Review of Hospital Safety and Quality Assurance in Victoria, 2016. ⁴⁰	https://www.dhhs.vic.gov.au/sites/default/files/documents/201610/Hospital%20Safety%20and%20Quality%20Assurance%20in%20Victoria.pdf	Technical Report	26 July 2019	<p>A report based on a review of the governance of quality and safety monitoring and data reporting throughout hospitals located in Victoria, Australia. The review process included stakeholder and expert consultation methods and the authors presented several recommendations, including the establishment of systematic collection of patient-reported outcome measures at a state-level.</p> <ul style="list-style-type: none">N/A: information related to barriers and enablers for PRO data was not included.
Duckett et al. Strengthening Safety Statistics: How to make hospital safety data more useful: The Grattan Institute, 2017. ⁴⁹	https://grattan.edu.au/wp-content/uploads/2017/11/893-strengthening-safety-statistics.pdf	Technical Report	26 July 2019	<p>A technical report focussed on methods to use to enhance the presentation of hospital safety data (in general), which also included information related to PRO data. The author suggested that aggregated data must be presented in a meaningful and simple ways and directed towards appropriate audiences who can take action.</p> <ul style="list-style-type: none">Barriers: the inclusion of statistical information and the assumption that clinicians will confidently interpret data without an adequate explanation or tailored training.Enablers: the identification of the audiences' needs and preferences and use of visual aids (e.g. line or bar graphs) were recommended for data reporting purposes to reduce information overload and increase the utility of the data.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Franklin et al. Framework to guide the collection and use of Patient- Reported Outcome Measures in the learning healthcare system, 2017. ⁴³	https://egems.academyhealth.org/articles/10.5334/egems.227/	Technical report	09 July 2019	<p>A report outlining the findings based on key informant interviews (conducted with 46 individuals who were actively engaged in the use of PROMs in diverse clinical settings), two interactive web-based discussions and an in-person workshop. The authors presented an implementation framework and included a toolkit of strategies to accelerate collection and use of PROMs.</p> <ul style="list-style-type: none"> Barriers: altered clinical workflows; limited web-based tools to support real-time scoring and trending of data across clinical settings, lack of data visualization tools. Enablers: the establishment and availability of population norms and benchmarks for PRO measures to compare data within and between specific clinical groups were outlined as enablers for use among clinicians, quality leaders and health system payers.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Nelson et al. Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case studies from Dartmouth, Karolinska and Group Health. Lebanon, New Hampshire: The Dartmouth Institute for Health Policy and Clinical Practice, 2012. ³⁹	https://www.researchgate.net/publication/232607583_Using_Patient-Reported_Information_to_Improve_Health_Outcomes_and_Health_Care_Value_Case_studies_from_Dartmouth_Karolinska_and_Group_Health	Technical report	11 July 2019	<p>A peer-reviewed, technical report outlining the feasibility, utility and lessons related to PROs data collection systems. The authors presented three case studies from PROs initiatives based at the Dartmouth-Hitchcock Spine (Lebanon), the Swedish Rheumatoid Arthritis Registry and Group Health Cooperative (Seattle, Washington).</p> <ul style="list-style-type: none">Barriers: the need for high adoption, completion and follow-up rates for PRO data, some clinicians may not know what to do with the results and decision support resources (e.g. clinical practice guidelines) need to be developed to guide responses to PROs results.Enablers: leveraging PROs by supplementing these data with other information sources (e.g. diagnosis data, biometrics), the use of standardized training materials for clinicians and co-designing data displays with end-users to promote utility of PROs among clinicians.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
NSW Agency for Clinical Innovation. Patient Reported Measures – Program overview, 2018. ⁴⁶	https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0004/415219/ACI18050_PRM_ProgOverview_Guide_v1.pdf	Program overview and guide	05 July 2019	<p>A guide and overview of the Agency for Clinical Innovation Patient Reported Outcome Measures program established in New South Wales, Australia. The document outlined implementation considerations related to PROs.</p> <ul style="list-style-type: none"> Barriers: PRO data collection and use may be duplicative or burdensome for clinicians, there may be a perceived lack of relevancy or meaning to clinicians, response rate issues. Enablers: routine reporting of PRO data back to clinicians to encourage them to take action. (e.g. with the ability to view data in real time and perform analytics of patient populations).

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Paxton Partners, Patient-Reported Outcome Measures: Literature scan, personal communication, 2018.	N/A	Report	14 June 2019	<p>A report based on the implementation considerations required for the establishment of a PROMs collection system in Victoria, Australia. The authors included a review of the literature and evidence from the experiences of early PRO data adopters located in other countries and jurisdictions.</p> <ul style="list-style-type: none">Barriers: variations in the approaches used to collect PRO data (e.g. the PRO measure used, the patient population, format and timing of feedback and the level of aggregation of the data), resources and costs required.Enablers: clinician engagement and the collection of PRO data via integration with existing data collection systems (e.g. clinical quality registries) to allow these data to be fed back and used at the micro-, meso- and macro-level.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Peterson A. Learning and understanding for quality improvement under different conditions - An analysis of quality registry-based collaboratives in acute and chronic care, 2015. ⁵²	http://hj.diva-portal.org/smash/get/diva2:871675/FULLTEXT01.pdf	Dissertation	08 July 2019	<p>A dissertation based on the use of Quality Improvement Collaboratives (QICs) in three national registries (which are also used for follow-up purposes) in Sweden. The author used an interactive approach to examine if, and how, QICs contributed to quality improvement in the provision of healthcare.</p> <ul style="list-style-type: none"> Barriers: issues related to missing or incomplete data in healthcare, lack of motivation among clinical teams, time constraints, staff turnover in clinical settings, clinicians need to know how to extract data from different systems. Enablers: continuous monitoring of a clinical teams' own data (in general) and ability to retrieve data in real time, learning from others and the formation of 'Communities of Practice' during quality improvement initiatives.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Raine et al. Patient-reported outcome measures and the evaluation of services. Challenges, solutions and future directions in the evaluation of service innovations in health care and public health: National Institute for Health Research, 2016. ⁵¹	https://www.ncbi.nlm.nih.gov/books/NBK361255/	Book/Book chapter	16 July 2019	<p>The authors provided an overview of the progress made in relation to PROs and outlined the main challenges that need to be addressed to further the field. Using the experiences and lessons learnt from several large-scale PROMs programs in different countries, the authors describe the role of PRO data and the need to engage clinicians to ensure uptake.</p> <ul style="list-style-type: none">Barriers: a lack of high-level evidence in the field of PROMs, a lack of integration of PRO data within health records and existing processes of care, missing or incomplete data (e.g. for sensitive questions), score interpretation difficulties and response shift bias.Enablers: the establishment of essential training and education mechanisms for clinicians to strengthen their understanding of PRO data and interpretation of results.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Snyder et al. Testing Ways to Display Patient-Reported Outcomes Data for Patients and Clinicians, 2018. ⁵⁵	https://www.pcori.org/sites/default/files/Snyder054-Final-Research-Report.pdf	Research Report	26 July 2019	<p>A final research report produced by a research team from the Patient-Centred Outcomes Research Institute (PCORI) in the United States. Using a three-part mixed methods study, the authors identified and tested a range of approaches for presenting PRO data (individual- and group-level) to promote understanding among clinicians and patients from cancer treatment settings.</p> <ul style="list-style-type: none"> Barriers: a lack of information is available to explain the methods used to determine clinical importance for PRO data, a lack of standardization related to scoring of PRO data and how these data are presented for use in clinical practice. Enablers: the provision of guidelines, work tools and education/training targeted towards different audiences to assist with PRO data interpretation.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
Thompson et al. Patient-reported Outcome Measures: An environmental scan of the Australian healthcare sector, 2016. ³	https://www.safetyandquality.gov.au/sites/default/files/migrated/PROMs-Environmental-Scan-December-2016.pdf	Final report (environmental scan)	14 June 2019	<p>A report based on an environmental scan of the literature undertaken by authors from the Australian Health Services Research Institute. The authors described status of the collection and use of PROMs initiatives in the Australian healthcare system.</p> <ul style="list-style-type: none">Barriers: a limited number of empirical examples of the application of aggregated PRO data for benchmarking purposes were found, patterns and case studies for PRO data collection were found to be variable.Enablers: the provision of timely reports, facilitation of benchmarking workshops for clinicians, a high level of clinician engagement and a willingness to integrate PROs within existing data collection systems.

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none"> Identified PRO data barriers Identified PRO data enablers
Williams et al. Patient-reported outcome measures: Literature review, 2016. ⁵	https://www.safetyandquality.gov.au/sites/default/files/migrated/PROMs-Literature-Review-December-2016.pdf	Final report (literature review)	14 June 2019	<p>A report based on the findings from a literature review conducted by researchers from the Australian Health Services Research Institute. The authors describe the international evidence to support the rationale for PROs data collections and different mechanisms used to facilitate collection, data uses and the impact of these data.</p> <ul style="list-style-type: none"> Barriers: the resources/costs required for PRO data collection, response burden/patient confidentiality concerns (e.g. sensitive questions), and time and workload constraints for clinicians to implement PROs into routine practice. Enablers: the use of integrated information technologies to support electronic capture of PRO data and real-time feedback to clinicians, training and support for clinicians to effectively use PRO data (e.g. increased familiarity with measures and interpretation of results).

Author/Organization, Title, Year	Web reference	Type of material	Date accessed	Brief summary/Relevant findings <ul style="list-style-type: none">Identified PRO data barriersIdentified PRO data enablers
World Economic Forum. Value in healthcare laying the foundation for health system transformation. Cologny/Geneva, Switzerland: World Economic Forum, 2017. ⁴⁸	http://www3.weforum.org/docs/WEF_Insight_Report_Value_Healthcare_Laying_Foundation.pdf	Report	05 July 2019	<p>A report based on a collaborative project undertaken by authors from the World Economic Forum and The Boston Consulting Group whereby the foundational principles of value-based health care, including information related to PRO data were described.</p> <ul style="list-style-type: none">Barriers: there is a lack of development of enhanced benchmarking methodologies for data (e.g. data collected through the use of clinical quality registry infrastructure).Enablers: interoperability issues and semantic interoperability issues related to linking data (in general) and for performing risk-adjustments to draw meaningful inferences from data (i.e. which can also be extended to PRO data).

Note. PRO: Patient-reported outcome. PROM: Patient-reported outcome measure.

Table 3. Summary of different PRO data presentation formats.

Graphical Format	Summary	Healthcare professional preference
Tables with numerical data	Presentation of data in tables is considered more neutral and needing less explanation for interpreting the meaning of the data than when presented in graphs. Tables with large amounts of data may be perceived as cluttered and lacking visual clarity, making them difficult to read. ^{31 34}	+/- Mixed
Use of icons/pictographs	Most healthcare professionals find tables with icons to be insufficient and lacking transparency. ^{31 33} This is the inverse to patients, who prefer such displays due to their simplicity. ³⁴	- Negative
Line graphs	Line graphs are the preferred approach for presenting individual patient PRO scores over time. ^{6 11 24 33 35 55} However, if there are too many outcome variables, the line graph may become difficult to interpret. ³⁷ The recommended maximum number of lines that should be displayed within a single graph is four. ²⁴	+ Positive
Bar graph	Bar graphs are widely liked as they are clear and facilitate comparison. ^{24 33} They can also easily include additional information (e.g. confidence intervals and descriptive labels). The use of confidence intervals should be accompanied by a written explanation to facilitate interpretation of the data. ³¹ To reduce confusion, the recommended maximum number of bars within a single graph should be six. ²⁴	+ Positive
Funnel plots	Funnel plots can provide a good overview, but also contain a lot of information. Those unfamiliar with funnel plots may find them confusing. ^{31 34 37} As such, the use of funnel plots should be accompanied by a detailed explanation of how to be interpreted.	+/- Mixed
Caterpillar plots	Caterpillar plots are less familiar to healthcare professionals and patients than bar graphs. ^{31 34} Though caterpillar plots are clearer than bar graphs containing confidence intervals, and can facilitate rapid comparisons between larger amounts of groups. ^{31 37}	+ Positive
Spider plots or radar chart	Healthcare professionals who are unfamiliar with spider plots may find them confusing and lacking clarity. ³¹ Spider plots also make displaying additional information such as confidence intervals or statistical significance difficult. ³¹	- Negative
Pie Charts and Stacked Bar Graphs	Pie charts and stacked bar graphs are both reasonable formats for presenting proportions visually, especially when there are big differences. ^{11 37} Healthcare professionals are more accurate at interpreting stacked bar graphs compared with pie charts, ³⁷ while patients can interpret pie charts more accurately. ²	+ Positive

Box 1. Summary of basic guiding principles

Recommendations to guide best practice in PRO data feedback to clinicians:

- Reporting PRO data back to clinicians should be done in a simple format that is easy to read to reduce the chance of misinterpretation.²⁵
- Features that may be used to facilitate simple reporting include: reducing the number of metrics presented within a report and minimising page counts.²⁹
- PRO reporting should avoid mixing the directions of scores that are displayed. Exceptionally clear labelling, titling and annotations should also be used to increase interpretability.^{2 11 35}
- The use of coloured arrows (e.g. green for better scores and red for worse scores) may enhance clinicians’ interpretation of PRO scores presented across different domains.³⁵
- Clinically significant differences and confidence intervals should be included where possible. There is a move away from reporting just the *p*-value.^{6 11}

Recommendations for optimal data presentation formats:

- The choice of which graphical format to use to display the PRO data, will depend on the type of data (i.e. single outcome/multiple outcomes, single time point/multiple time points, amount of data to display etc.) and the intended purpose of the data.²⁴
- Line graphs and bar graphs are preferred and reduce the chance of misinterpreting the data.^{24 33}
- The maximum number of bars presented within a bar graph should be 6, while the maximum number of lines within a line graph should be 4.²⁴
- More complex displays such as funnel plots or caterpillar plots should be accompanied by a description of how to interpret the graph.³¹

Recommendations to address barriers and enablers associated with feedback and reporting of PROs:

- The inclusion of clinical/local champions is critical to generate buy-in from the clinical community (Aspex Consulting, Evaluation Framework and Initial Appraisal of PROMS: Final Report, personal communications, 2018).
- PROs should be reported in a way that can be directly translated into specific actions to guide clinicians to respond to concerning results.^{26 28}
- Training and education are needed to improve the clinician’s ability to interpret PRO data, to integrate the use of PROs into their routine practice, and to respond to concerning results.^{39 51}
- The optimal time intervals for PRO feedback needs to be determined. One suggested timeframe for audit and feedback to clinicians is 1 to 4 times a year.³⁷

Legend: Figure 1 shows the study identification and selection process that was applied to the academic literature during the study. The original database search resulted in 4445 records identified. An additional 4 records were identified from other sources. After duplicates were removed, there were 3480 unique records. The title and abstract screening process excluded 3191 records for being unrelated to the topic. The remaining 289 records underwent the full-text screening process, where 270 records were excluded for the following reasons: 31 were not about patient reported outcomes, 159 did not feed back the patient reported outcomes, 21 were the wrong article type, 11 were the wrong article setting, and 2 records were not in English. 19 unique records were included in the final synthesis.

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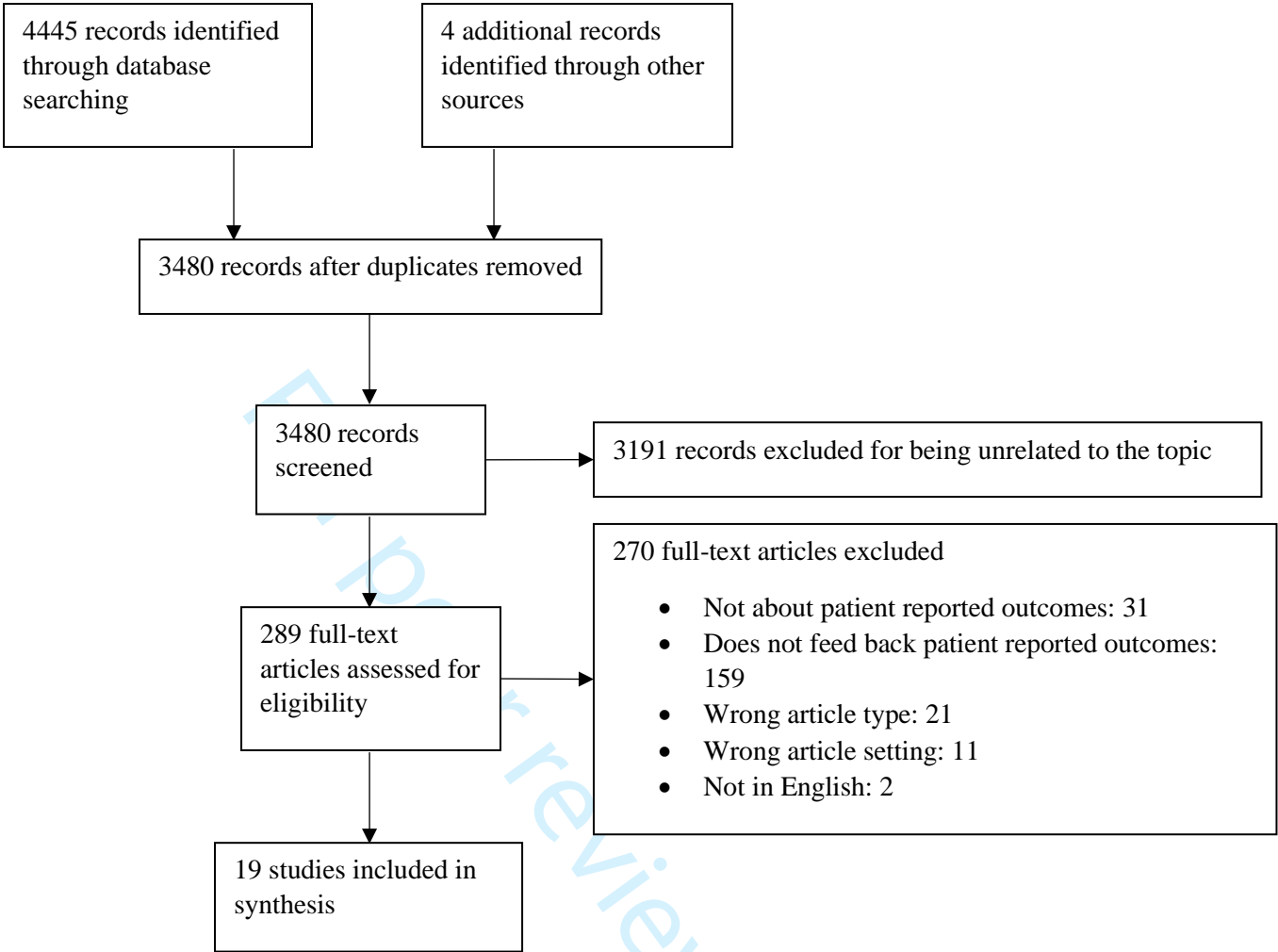


Figure 1. PRISMA flow chart illustrating findings from the academic literature search²³

Appendix 1. Data extraction tool used for academic literature

	Description
Author	
Year	
Title	
Country	
Type of Article	
Characteristics of patient	
Characteristic of professional	
Clinical area of practice	
Characteristic of study	
Number of participants (included, excluded, partially followed up and lost)	
Unit of analysis	
Level of feedback (individual [micro]/group-level [meso]/population level [macro])	
Feedback for patient/clinician	
Type of PRO(M) used	
Purpose of feedback (influence patient relations, change clinical practice etc)	
Findings related to existing evidence on best practice in the readability and feedback of PRO data to healthcare professionals	
Findings related to what PRO data presentation formats were used	
Findings related to factors that influence PRO data interpretation or use in clinical practice	
Additional notes	

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Appendix 2. Data extraction tool used for the grey literature

	Description
Author/Organization	
Year of publication	
Title	
Country	
Type of document	
Date of access	
URL	
Background Patient Reported Outcome Measures information	
Patient Reported Outcomes data display features	
Patient Reported Outcomes data feedback mechanism(s)	
Identified barriers to Patient Reported Outcomes data uptake among clinicians	
Identified enablers to Patient Reported Outcomes data uptake among clinicians	
Patient Reported Outcomes data issues (e.g. statistical/analytical methods)	
Additional notes	

Supplemental Table 1. Breakdown of academic literature search strategy and key words.

Database	Search string	Results
Embase	Patient-reported outcome measures Patient reported outcomes PROMs PROM PROs PRO 1 or 2 or 3 or 4 or 5 or 6 – 213251 results Patient-centered care Patient centred care Health care policy Value based health care Low value care Quality of care Health care quality Quality improvement 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15– 112842 results Feedback Audit Review Benchmark Practice data Hospital* data Dashboard Dash board Public* report* 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 – 7 and 16 and 26 - Limit 27 to (English language and yr="2009-Current")	905
Ovid Medline	1. Patient-reported outcome measures 2. Patient reported outcomes 3. PROMs 4. PROM 5. PROs 6. PRO 7. 1 or 2 or 3 or 4 or 5 or 6 – 213251 results 8. Patient-centered care 9. Patient centred care 10. Health care policy 11. Value based health care 12. Low value care 13. Quality of care 14. Health care quality 15. Quality improvement 16. 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15– 112842 results 17. Feedback 18. Audit	390

	19. Review 20. Benchmark 21. Practice data 22. Hospital* data 23. Dashboard 24. Dash board 25. Public* report* 26. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 – 27. 7 and 16 and 26 - Limit 27 to (English language and yr="2009-Current")	
Scopus	TITLE-ABS-KEY ("Patient reported outcome measures" OR "patient reported outcomes" OR "PROMs" OR "PROM" OR "PROs" OR "PRO") AND ("patient centered care" OR "patient centred care" OR "health care policy" OR "value based health care" OR "low value care" OR "quality of care" OR "health care quality" OR "quality improvement") AND ("feedback" OR "audit" OR "review" OR "benchmark" OR "practice data" OR "hospital* data" OR "dashboard" OR "dash board" OR "public* report") AND (LIMIT-TO (DOCTYPE , "ar") OR LIMIT-TO (DOCTYPE , "re") OR LIMIT-TO (DOCTYPE , "ed") OR LIMIT-TO (DOCTYPE , "cp")) AND (LIMIT-TO (SUBJAREA , "MEDI") OR LIMIT-TO (SUBJAREA , "HEAL")) AND (LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009)) AND (LIMIT-TO (LANGUAGE , "English"))	2896
Web of science	TOPIC: (("patient reported outcome measures" OR "patient reported outcomes" OR "PROMs" OR "PROM" OR "PROs" OR "PRO") AND ("patient centered care" OR "patient centred care" OR "health care policy" OR "value based health care" OR "low value care" OR "quality of care" OR "health care quality" OR "quality improvement") AND ("feedback" OR "audit" OR "review" OR "benchmark" OR "practice data" OR "hospital* data" OR "dashboard" OR "dash board" OR "public* report*")) Timespan: 2009-2019	220

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3-4
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	4
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	4
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	4,5
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	4,6
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplementary table
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	5
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	5,6,7
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	5,6
Critical appraisal of individual	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe	6

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
sources of evidence§		the methods used and how this information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	7
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	7, Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Table 1
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Table 1
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Table 1
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Table 1, 8-14
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Box 1, 14-16
Limitations	20	Discuss the limitations of the scoping review process.	16
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	17
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	2

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.
 * Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.
 † A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).
 ‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.
 § The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*. 2018;169:467–473. doi: 10.7326/M18-0850.